

**NEEDS ASSESSMENT OF THE
MCH POPULATION
2010**

**PUERTO RICO TITLE V
APPLICATION
2010-2011**

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II. NEEDS ASSESSMENT (2005-2010)

INTRODUCTION

The Puerto Rico MCH Program (PRMCH) is an essential public health program, since it is responsible for over 50% of the population comprised by women in their reproductive age, their infants, children, adolescents, and children with special health care needs. The MCH program has to assure that health services are available, accessible and responsive to the needs of MCH populations according to the most current established standards of care. Since the 1993 PR health care reform, the major public health functions of PRMCH are assessment, applied research, health education and promotion, informing public policy and assurance. It is worth noting that a new health care plan initiative called “Modelo Integrado de Salud” (Integrated Health Model) is underway in Puerto Rico. Given the newly public health care plan and changes in PRMCH public health functions, assurance of service availability and accessibility becomes a challenging task within the context of a very complex and changing public health care system.

As a recipient of federal Title V Maternal and Child Health Services Block grant funds, Puerto Rico is required to complete a needs assessment and submit a report every five years on the process and results regarding MCH populations’ needs, system capacity, priorities, outcomes, performance measures and a plan to guide actions and policymaking. Puerto Rico’s five year needs assessment, referred to as PRMCH2010 covers the period 2005 to 2010 and has resulted in the identification of the priority needs of the MCH target populations, strategies to meet those needs, and the state performance measures and outcomes. The target populations groups are:

- A. Pregnant women, reproductive age women, and infants
- B. Children and adolescents.
- C. Children with special health care needs (CSHCN)

Considering the particularities of children with special health care care needs, Puerto Rico used a separate process for the needs assessment of the general MCH and CSCHN populations including system capacity analysis. The Evaluation, Monitoring, Research and System Development Section (EMRSDS) in collaboration with other research and program staff carried out the assessment for the General MCH populations (pregnant women, reproductive age women, infants, children and adolescents). The CSHCN Section researchers conducted the assessment for the children with special health care needs population group. A two part needs assessment report has been prepared and submitted to the Maternal and Child Health Bureau: Part I. General MCH Populations Needs and System Capacity Assessment and; Part II. CSHCN Population Needs and System Capacity Assessment.

PART I.

GENERAL MCH

POPULATIONS NEEDS

AND

SYSTEM CAPACITY ASSESSMENT

General MCH Populations Needs and System Capacity Assessment

1. PROCESS FOR CONDUCTING NEEDS ASSESSMENT

a. Vision, Goals and Framework

The mission of the PRMCH is to promote the optimal health status and well being of all women of reproductive age, infants and children (including children with special health care needs), adolescents and families residing in Puerto Rico. Given its mandate to assure healthy families in Puerto Rican society, PRMCH is responsible to assess their needs and address its resources to enhance the health of the target populations.

The PRMCH, through the health needs assessment (2010 HNA), aims to identify, analyze and present up-to-date information about the major needs of each of the MCH population groups and to evaluate the capability of the system to provide and support needed health care and related services. The 2010 HNA resulted in two critical goals for the PRMCH:

1. Determine Puerto Rico's priority needs for the MCH populations
2. Improve health outcomes for the MCH populations
3. Strengthen partnerships with agencies and organizations that have interest in the well being of MCH populations and their families.
4. Enhance the stakeholders' participation in all aspects of the needs assessment.

The framework used to conduct the 2010 HNA of the general MCH populations was developed around three broad phases. Emphasis was placed around obtaining input from stakeholders of various capabilities and experiences at every phase of the process. The assessment phases are:

1. Assessment of the Needs of MCH population groups. This phase involved the collection and analysis of both quantitative and qualitative data for each population group – pregnant women, reproductive-age women, infants, children and adolescents.
2. Assessment of the Capacity of the System to meet MCH population needs. This phase involved the evaluation of the capacity of the broader system to meet the identified MCH population needs, as well as identifying the strengths and challenges faced by PRMCH in relation to the core MCH functions.
3. Setting potential priorities based on the assessment of needs and capacity. This entailed narrowing potential needs priorities and matching needs to capacity, setting targets, identifying activities and/or actions and allocating resources.

This three-phased framework provided a structure that enabled PRMCH to determine the priorities needs, assess existing internal and external resources, and establish desired outcomes and performance measures to monitor health status. It also enabled PRMCH to

better grasp the factors that promote or impede the health and well being of the population groups, and acknowledge its own strengths and challenges in health promotion.

The information from this needs assessment served as a guide to the decision-making process on whether, and in what way introduce programmatic changes and to develop and implement a well-thought and realistic plan of action at the Central and Regional levels.

b. Leadership

The health needs assessment is an-going process carried out on a year-round basis. This work is performed mainly by the PRMCH research team - housed in the Evaluation, Monitoring, Research and System Development Section (EMRSDS) - that monitors changes in the health status of the target population based on the analysis of qualitative data, surveillance system data, linked data sets, and other relevant surveys. The team consists of a Demographer, which is the SSDI and Section Coordinator, a Biostatistician, a Reproductive Health Epidemiologist, a Pediatric Epidemiologist, a Health Program Evaluator, and an Applied Cultural Anthropologist. Throughout the year, the research team works closely with other program staff, program-specific researchers (i.e. Evaluators and Epidemiologists), the Programmatic Coordinator (Pediatric Consultant) and PRMCH Director to monitor the progress of all performance and outcome measures, as well as the level of progress in improving the health and well-being of the MCH population groups.

The EMRSDS team played a key role in conceptualizing, organizing, and carrying-out the 2010 HNA. This work was done with support from the MCH Programmatic Coordinator who served as consultant in the needs assessment process. The MCH Director monitored the work and held regular meetings with the EMRSDS team.

As part of the efforts for the 2010 HNA, an internal steering committee was organized. This committee consisted of EMRSDS researchers, the Programmatic Coordinator, CSHN research staff and Director, MCH Director and staff from several PRMCH programs. The steering committee held several meetings to discuss the way to conduct the needs assessment, stages in needs assessment, process of setting priorities, target populations and a more in depth qualitative methodology into the process. Two sub-committees were formed corresponding to the General MCH populations. These subcommittees were: a) Pregnant women, Mothers and Infants, led by EMRSDS Coordinator and; b) Children and Adolescents, led by the Programmatic Coordinator. Each subcommittee charge was to analyze existing data, determine what new data was needed, and determine the sources of data for each specific population group.

Once the work of the subcommittees was done, EMRSDS proceeded to compile the analyzed data from a variety of sources. The applied cultural anthropologist organized a Qualitative Workgroup - composed of the EMRSDS Evaluator, CHSN Evaluator, Healthy Start Social Worker, and Healthy Start Program Evaluator - to engage specifically in conducting health dialogues with different groups of stakeholders. The Applied Cultural Anthropologist led the work of the Qualitative Workgroup; she designed the qualitative procedures to gather information and guided other members in qualitative interviewing methods.

After all data was gathered and analyzed, the EMRSDS team organized and facilitated a two-day priority setting meeting with a group of stakeholders. Once the potential priorities were narrowed down and possible strategies were identified by stakeholders, the MCH Director organized an internal General MCH Population Workgroup to examine and make decisions about the potential needs identified and the performance measures to monitor progress. This group consisted of MCH Director, the Programmatic Coordinator and EMRSDS researchers.

The EMRSDS Epidemiologists, Biostatistician, and Program Evaluator performed the statistical and trend analyses of quantitative data. The EMRSDS/SSDI Coordinator performed the analysis for the System Capacity and the integration of the quantitative information. The Applied Cultural Anthropologist made the qualitative analysis and wrote the parts pertaining to the qualitative information concerning the general MCH groups and the strengths and challenges of PRMCH. She also offered assistance in editing the report.

c. Overall Methodology of Needs Assessment

The Steering Committee agreed on conducting a wide-ranging assessment of health-related needs of the MCH population groups in order to assure a comprehensive process in the identification of needs, setting priorities and adopting measures to monitor improvement. Several steps - within each broad phase - were undertaken to achieve results.

Phase One: Assessment of MCH population needs:

- As mentioned earlier, two subcommittees corresponding to each group within the general MCH populations were formed. The committees reviewed Title V conceptual framework (pyramid levels), indicators and measures in relation to each population group and sub-group.
- In-depth review of the documents produced by different programs (e.g. the Home Visiting Program, Healthy Start Consortium, Comprehensive Adolescent Program, MCH Regional Directors, and MCH Regional Boards). The Teams reviewed the general public policies, MCH investigations, formal and informal reports on progress or achievements of MCH Programs, current guidance's, 2005 Puerto Rico Needs Assessment, other Needs Assessment studies, and scientific literature concerning to MCH population and needs assessment. The review process was guided by several tools including, but not restricted to, HP 2010 National Healthy Objectives related to the MCH population contained in Focus Areas 9, 16 and others; the 18 National PMs and 9 State negotiated PMs; 12 health status and 9 health systems capacity indicators; 6 national and one state outcome measures. This step aided to assess the magnitude of health status, strengths and needs of the target populations.
- Determined data gaps and identified the sources for additional types of data. Letters of inquiry were sent to different programs within and outside the Health Department that keep databases to analyze quantitative data.

- Developed instruments and guides to collect data from stakeholders. A Health Indicators Questionnaire was developed and distributed among members of the PRMCH Regional Boards to identify needs/problems that MCH should address as potential priorities. Health dialogues guides and key-participant interview schedule were developed to gather qualitative information from stakeholders. Based on these quantitative and qualitative procedures we obtained about 42 potential priorities.
- Obtained stakeholders input by a wide array of activities such as interviews, health dialogues, surveys, written input obtained at conferences and meetings. A majority of the stakeholders involved in the needs assessment form part of PRMCH structure (program staff from central and regional levels, program participants, and board and/or committees members). Also, pediatricians that participated in the PR Annual Meeting of the American Academy of Pediatrician Puerto Rico Chapter provided information about the most frequent health conditions in children based on the medical visits.
- Analyzed quantitative and qualitative data on the health needs of the general MCH populations.

Phase Two: Assessment of the System Capacity

- Identified - at state and local levels - all activities, services and programs according to the MCH pyramid levels for each of the general MCH population groups. A table was constructed with data of agencies. This list of sources of secondary data included demographic, socioeconomic and environmental information, health services utilization, surveys and research concerning the MCH population.
- Developed and distributed among PRMCH program coordinators a questionnaire to assess the infrastructure building capacity of PRMCH.
- Analyzed the data pertaining to system capacity that was gathered through the Health Indicators Questionnaire given to the Regional Boards. This instrument also collected data on the agencies/programs that tackle MCH population health needs.
- Analyzed the qualitative data gathered about the strengths and challenges faced by PRMCH programs and Regional Boards. This data was gathered during the health dialogues that addressed health needs as well as strengths and challenges.

Phase Three: Setting needs priorities

(See section 5, Selection of State Priority Needs for detailed information on this process).

- Periodic meetings were held by the EMRSDS team to discuss the findings and the procedures to select the ten priorities.
- A list of problems/needs (based on quantitative and qualitative data) was developed.
- Reviewed a variety of instruments used in other states to set needs priorities.

- Translated and culturally adapted the Needs Prioritization Method instrument used by Louisiana State (2005). This instrument considered the extent of the problem, severity, acceptability, and resource availability as criteria to discuss and arrive at priorities.
- Convened a two-day stakeholder meeting – both from within and outside PRMCH - to discuss and narrow potential needs priorities.
- A General Population Workgroup was organized to discuss the potential priorities identified by the stakeholder meeting. The group established selection criteria, identified priority needs and set state performance measures. This team consisted of EMRSDS researchers, the MCH Director, and the Programmatic Coordinator.

d. Needs Assessment Methods and Data Sources

The 2010 HNA used quantitative and qualitative methods to collect information on the health needs of MCH population groups and the capacity of the system to meet the identified needs. This resulted in a more comprehensive picture of the population's health status and needs in relation to PRMCH functions and overall system capacity.

Quantitative methods and data sources to assess MCH populations' needs

For the needs assessment, MCH population needs and health status were analyzed using statistical methods and data from a variety of sources and tools. The statistical methods include percentages and rates of health indicators, odd ratios and trend analysis. Trend analysis was performed of selected indicators such as mortality rates by age group, birth rates, prenatal care, LBW and very low birth weight and unintentional injuries.

The quantitative analysis for women in reproductive age (WRA), and mothers (based on PM, SPM, OM HP2010) generated about 5 general indicators such as population characteristics, health status (preconceptive care, folic acid use, oral health, PAP screening, mammography screening, ETS, Domestic Violence), health behaviors (Tobacco and alcohol use, physical activity), Maternal mortality, maternal morbidity, and factors related to pregnancy (hospitalization, prenatal care, breastfeeding, cesarean, and family planning).

For the infants, the indicators were: population characteristics, mortality by age at death and causes of death, morbidity issues including vaccination, hereditary diseases, and congenital defects.

The indicators for children and adolescents were: morbidity and mortality for preschool children (1-4 years), school age children (5-14 years) and adolescents (10-19 years). For the adolescent population other indicators were analyzed. These were: ambulatory care and hospitalizations, risk behaviors (violence and suicide, tobacco, alcohol and drug use and abuse), sexual behaviors (adolescent pregnancy, sexually transmitted infections, syphilis and gonorrhea), and injury (unintentional injuries).

We collected population-based data that are comprehensive in scope such as PR Vital Statistics (VS) database (birth, death, fetal death and infant mortality). The Vital Statistics

database is the source of about 75% of the data for the National and State Performance Measures, Outcome Measures, Health System Capacity Indicators, and Health Status Indicators. In the 2010 HNA the VS was also used to identify health needs of pregnant women, mothers and infants. Moreover there are limitations on relying solely on birth and death certificates databases. Therefore, we also relied on data collected by agencies and programs – governmental and non-governmental - providing services to MCH population groups. These agencies and/or programs provided data on morbidity, lifestyle, screening and risk factors. The agencies and/or programs that provided the data were the following:

Agencies/Programs outside the Puerto Rico Department of Health

- The Puerto Rico Community Survey: The Puerto Rico Community Survey (PRCS) is the equivalent of the American Community Survey (ACS) for Puerto Rico. It began data collection in 2005. The ACS is a survey of the US Census Bureau that provides critical economic, social, demographic, and housing information collected in every county, American Indian and Alaska Native Area, and Hawaiian Home Land. Data results from both the ACS and the PRCS are released together as a unified American Community Survey dataset.
- Healthy People 2010. Healthy People 2010 are a set of health objectives for the Nation that can be used by many different people, States, communities, professional organizations, and others to help them develop programs to improve health.
- Maternal Infant Oral Health Center (CSOMI). CSOMI focus on early prevention of oral conditions in pregnant women and children. CSOMI offers dental services to mothers in their first phase of pregnancy and children 3 years old and younger. In addition of oral health services, education of prevention of oral diseases and nutrition are offered.
- Health Insurance Commissioner Office (HICO). HICO is responsible to regulate and evaluate the services offered by the private health insurances in Puerto Rico. The HICO compiles claims data from private health insurance companies for women in reproductive age, pregnant women, infants, children and adolescents.
- PROFAMILIA (Profamily). PROFAMILIA, a private non-profit organization offers sexual and reproductive health services – birth control, education and toll free line- to low- income population. The program furnishes data about birth control distribution among reproductive age women.
- Police Department. The Police Department provides data of domestic violence and crimes stratified by age group.
- Department of Education. This department provides the total number of students enrolled per school year, number of dropouts and reasons, and the total of students with special health care needs.
- Head Start Program. The Head Start Program provides comprehensive education, health, nutrition, and parent services to low-income children and their families. This

program provides information related to the most prevalent health conditions among its participants.

Agencies/Programs within the Puerto Rico Department of Health

- Health Services Administration (ASES). ASES is part of the implementation of the Governmental Health Insurance Plan (GIP) whose responsibility is responsible to evaluate and regulate this insurance around the Island. This program provided data on reproductive age women, pregnant women, infants, children and adolescents that are eligible and insure by GIP. Medicaid funds PR receives are capped and fall short to provide all Medicaid eligible population the GIP medical insurance benefit. Therefore, a significant amount of state and municipal funds must be expended to purchase medical insurance benefits for all the population with incomes below 200% SPL. This situation and the fact that the GIP uses a captivated managed care system model makes it difficult for ASES to separate claims data generated by Medicaid vs. Non-Medicaid population.
- Sexual Assault Victim Center (CAVV). CAVV educates and offers direct individual and group therapy to survivors of domestic violence and/or sexual aggression of any age. The center also provides public education and professional trainings. This program provides information of domestic violence victims (survivors) and the offenders.
- Administration of Mental Illness and Anti-Addiction Services (ASSMCA, Spanish acronym). ASSMCA provides direct services in substance abuse and other mental health conditions. This agency also develops prevention programs related to mental health and substance abuse with the objective of promoting and keeping the bio-psycho-social health of populations in Puerto Rico. Yet, ASSMCA services are limited and fail to meet the need for mental health services in the population. This agency provides information about the most prevalent mental health conditions among the maternal, infant, children and adolescent population.
- PR WIC Program. WIC is part of the Food and Nutrition Services Department and it offers nutritional services to women in different phases since pregnancy period, breastfeeding period or postpartum period, as well as to children until 5 years of age. This program provides the most prevalent health conditions among its participants.
- Puerto Rico Hereditary Disease Program. The Puerto Rico Hereditary Disease Program performs screenings to detect congenital hypothyroidism, phenylketonuria (PKU), Sickle Cell, galactosemia, and congenital adrenal hyperplasia. Efforts aimed at adding other screening tests for other metabolic diseases using the mass spectrometry (MS/MS) are in course.

- Puerto Rico Immunization Program: The Puerto Rico Immunization Program is responsible of buying, storing and supplying vaccines to all providers of immunization services of the Governmental Health Insurance Plan (GIP). This program monitors the way providers manage these services and performs auditions to ensure that services are provided according to standards established by the Advisory Committee on Immunization Practices (ACIP) and CDC.
- Program of Comprehensive Services to Families with HIV/AIDS: This program informs the number of women that were screened with HIV, number of pregnant women screened with HIV, number of pregnant women with HIV that received treatment and total of live births and infected live births with HIV.

Research outside PRMCH

- Monitoring the Future. Since 1990 Puerto Rico have a program of school surveys called “Monitoring the Future”. This program consists of biannual school surveys designed to monitoring the substance use in adolescents and its risk and protective factors. The sample is representative of elementary, middle and high schools in Puerto Rico. The periodic repetition of this survey, allows the evaluation of the patterns of substance use among schoolchildren and its changes over time. Monitoring the future is a project of the Administration of Mental Illness and Anti-Addiction Services (ASSMCA). The investigation phase is part of a group of investigators the Central University of the Caribbean and the University of Puerto Rico. This study provides the results related to risk behaviors among the adolescent group.

PRMCH Research

- PR Maternal Infant Health Survey (ESMIPR). ESMIPR is a customized PRAMS-like survey designed to collect primary data concerning the health and behaviors of recent mothers that influence maternal and birth outcomes. The last survey was conducted from March to June 2008 in a representative sample of 31 birthing hospitals, which had at least 10 deliveries per week in 2005. A total of 1,876 recent mothers in the postpartum ward answered a self-administered questionnaire. A limitation of this study is that the data is not representative of the entire population since the sample is non-probabilistic.
- Prevalence of Neural Tube Defects (NTD) and Folic Acid Knowledge and Consumption, Puerto Rico, 1996-2006. In 2008, with the objective of assessing trends in NTD prevalence at birth and prevalence of knowledge and consumption of folic acid supplements in Puerto Rico (PR), data from the PR Birth Defect Surveillance System (BDSS) and vital statistics records were used to calculate total annual NTD prevalence at birth as the number of spina bifida or anencephaly cases (including live births, fetal deaths, stillbirths, spontaneous abortions, and elective terminations) per year, multiplied by 10,000 and then divided by the number of live births for each year. To assess folic acid knowledge and daily folic acid

consumption among non pregnant women aged 18-44 years in Puerto Rico, data were collected from the BRFSS surveys administered in 1997-1998, 2000, 2002-2004, and 2006. Statistical estimates were weighted to reflect the total population of women aged 18-44 years in PR. Differences in data points were considered statistically significant at $p < 0.05$ by chi-square test.

- Evaluation of the Folic Acid Knowledge and Consumption among women of reproductive age in Puerto Rico, 1999-2004. Other study (2007) was developed with the objective of comparing the folic acid knowledge and consumption between mothers with NTD affected pregnancies and mothers from the general population. Data from PR BDSS Genetic Counselor interviews to mothers with birth defects affected pregnancies were used to determine the folic acid consumption and knowledge of these mothers. We determined folic acid use assessing the percent of mothers that reported using folic acid at least 3 months prior the NTD affected pregnancy. The folic acid knowledge in this population was assessed determining the percent of mothers that knew (at the moment of the interview) that folic acid helps prevent birth defects.
- Comparison of Prenatal Care and Birth Outcomes in Participants of the Healthy Start Project and a Control Group, 2001. The Healthy Start Program completed a study during 2005-2006, where the participants were compared to a control group of non-participants in the same population in a series of indicators included in the IIMIHS (number of prenatal care, visits, birth and pregnancy outcomes and infant mortality rates). One was conducted in 2001 comparing birth outcomes of HVP participants ($n=1,052$) with a no-treatment equivalent control group ($n=1,052$) matched by age, educational level and source of payment for health services.
- Descriptive Study of Birthing Methods, Puerto Rico, 1990-98. A descriptive study was carried out to provide updated information to concerned individuals and organizations to generate discussion regarding the possible causes that lead to the increased use of this birthing method in Puerto Rico. Stratified analyses from linked birth and death files provided by the State Vital Statistics Office were performed using the most relevant data available to describe the picture and to generate hypotheses regarding the problem. A total of 183,400 c-section live births were evaluated for the 1990-1998 period.
- Election of Childbirth by Cesarean Delivery: Attitudes and Experiences of the Woman and Physician Characteristics in the Decision Making. Recommended by the C-section Committee. It is a survey of women subjected to c-section. From July 2004 to February 2005 the MCH staff conducted the study. The study looked for associations between attitudes and experiences of the woman and the characteristics of the physician in the decision making to deliver by c-section. The methodology consisted of a self-administered questionnaire that collected socio-demographic data, medical history, prenatal care utilization, experiences before and during pregnancy, delivery information, newborn data, and the mother's opinion about and preference for the type of delivery. It was submitted to 1,004 primiparous women

(502 cases and 502 controls) who had a live birth in 31 hospitals that registered 10 births or more per week during 2002.

- Integrated Index of Maternal and Infant Health Status (IIMIHS) by Municipality. In order to assess the maternal and infant health status and to compare it by municipalities, an index was developed by the MCH Division in 1998. The Index includes 15 indicators selected from birth and death files. The IIMIHS is comprised of five sociodemographic indicators: (1) Birth rate, (2) Percent of unmarried women, (3) Percent of adolescent mothers, (4) Percent of unmarried adolescent mothers, and (5) Percent of mothers with less than 12 years of education. Two are related with the adequacy of prenatal care: (1) First trimester admission rate, and (2) Kotelchuck Index. The remaining eight reflect the pregnancy outcome indicators: (1) Percent of prematurity, (2) Percent of VLBW, (3) Percent of LBW, (4) Neonatal mortality, (5) Postneonatal mortality, (6) Infant mortality rate, (7) Stillbirth rate, and (8) Perinatal mortality rate.

Making use of available data from birth and death files, the value of each of the 15 indicators is determined for the 78 municipalities. These are ranked according to the value of the indicator. The sum of all the 15 ranks obtained by a municipality constitutes the IIMIHS. In theory, if a municipality ranks in the first position for each selected indicator it would have an IIMIHS of fifteen (15). In the contrary, if it ranks in the last position (78) for each indicator it would have an index of 1,170. The IIMIHS has been used as a tool for the allocation of resources and to raise awareness among different stakeholders regarding maternal and infant health across different geographical areas.

- Satisfaction Study of the Healthy Start Project Clients, 2007-2009. A cross-sectional study which used a self-administered questionnaire to determine the satisfaction of participants with the services provided by the Home Visiting Program. The questionnaire is given to every participant a week before her discharge from the Home Visiting/Healthy Start Program.
- The Puerto Rico Health Survey. The Puerto Rico Health Survey was created on 1963. The objective of this survey was to measure some health indicators to obtain a description of the population of Puerto Rico (including the pediatric population) that facilitate planning and administration of health services. This study provided the morbidity data among the uninsured population aged 0-19 years.
- Obesity prevalence, nutrition habits and physical activity in 2nd, 5th, 8th, and 11th grade students, Puerto Rico school year 2008-2009- The MCH Division in collaboration with the Alliance for Healthy, Active and Well Nourished Children and Adolescents (AHAWNCA) developed a study in the school year 2008-2009. The main purpose of this study is to estimate the prevalence of obesity, overweight, healthy weight and underweight among students of second, fifth, eighth and eleventh grade. Also this study describes the nutritional habits and the physical activities of students and their families. This study provided the preliminary results of overweight and obesity prevalence among the second and fifth graders.

Surveillance Systems

- PRMCH Birth Defects Surveillance System (BDSS). The BDSS is a population-based active surveillance system that assesses approximately 48,000 births each year. The abstractors visit all PR birthing hospitals weekly; and 99.7% of babies are born in these hospitals. This surveillance system compiles epidemiologic data of forty four (44) congenital conditions diagnosed at birth. Although most of the reported conditions are screened before hospital discharge, in some cases diagnoses may be confirmed later during childhood, up to six (6) years of age. One of the strengths of this data source is that is an active surveillance system, and as of September 2004 reporting these conditions is mandatory by Law #351. However, due to its recent implementation, it may be unknown by many physicians. The main limitation with the birth defects database is that some conditions are not included until the diagnosis is confirmed and the rates per condition could vary through this period during the year.
- PRMCH Asthma Surveillance System. The Puerto Rico Asthma Project - subsidized by the CDC - main goal is to reduce the asthma burden and improve the quality of life of the persons with asthma in Puerto Rico. Through this project, the Puerto Rico Asthma Control Strategic Plan and the Asthma Surveillance System were developed with the collaboration of the Puerto Rico Asthma and Other Chronic Respiratory Diseases Coalition.
- Youth Behavioral Risk Factor Surveillance System The Youth Risk Behavior Surveillance System (YRBSS) monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults. The YRBSS includes a national school-based survey conducted by the Centers for Disease Control and Prevention (CDC) and state, territorial, tribal, and district surveys conducted by state, territorial, and local education and health agencies and tribal governments. The Youth Risk Behavior Surveillance System (YRBSS) monitors six categories of priority health-risk behaviors among youth and young adults including: behaviors that contribute to unintentional injuries and violence; tobacco use; alcohol and other drug use; sexual behaviors that contribute to unintended pregnancy and sexually transmitted diseases (STDs), including human immunodeficiency virus (HIV) infection; unhealthy dietary behaviors and physical inactivity.
- The Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is a state-based system of health surveys that collects information on health risk behaviors, preventive health practices, and health care access primarily related to chronic disease and injury. This survey does not include cellular phone numbers in the sample, which is a limitation since many households in Puerto Rico have eliminated residential telephones and rely solely on cellular phones.

- Puerto Rico Sexually Transmitted Diseases (STDs) Surveillance System: The Puerto Rico STDs Surveillance System monitors and follows up cases reported with an STD. Data of Syphilis, Congenital Syphilis Chlamydia, Gonorrhea, and Herpes among others are reported by sex and age.

Health Indicators Survey

In addition to obtaining information from a variety sources, a Health Indicators Questionnaire was developed to collect data from stakeholders in order to identify needs that MCH should address as potential priorities. Specifically this questionnaire listed, for each subgroup of MCH population, different protective and risk indicators according to the analysis performed and the findings of studies during the last 5 years.

Qualitative methods and data sources to assess MCH populations' needs

The qualitative methodology refers to the field of knowledge, approaches, and methods emerging from different disciplines within the Social Sciences. Qualitative research aims at gaining insights into people's behavior, perspectives and experiences in natural settings. Emphasis is placed on how people perceive and construct their lives, how people interact with one another and interpret these interactions in the context of socio-cultural relations. Typically it involves face-to-face interaction with research participants and asks open-ended questions to allow participants to respond in their own words about their experiences, perceptions and knowledge related to the phenomena being studied. Open-ended questions induce responses that are meaningful and culturally relevant to participants that may be unanticipated by researchers who, in turn, can respond immediately to what participants say by tailoring subsequent questions to the information provided. Qualitative research follows a cyclical-step (non-linear) procedure that is flexible, dynamic and iterative (research questions and procedures are adjusted according to what is found in fieldwork). Multiple data collection methods and sources (triangulation) are often used in the same study. Qualitative reports are typically rich in detail, insight, and incorporate the voices of people in the text (Taylor & Bogdan, 1987; Wolcott, 1994; Bernard, 2002; Ulin, Robinson & Tolley, 2005).

Qualitative methods fill a gap in public health in that they help us understand experiences, behaviors, attitudes, perceptions, and beliefs influencing health and health seeking behavior among target populations. They also provide insights into the meanings of decisions and actions of beneficiaries of health-related services. Similarly, they provide insights into the perceptions, explanations and experiences of those providing health-related services. Qualitative methods also provide a deeper understanding of health policies and programs and how responsive or unresponsive they are in helping people improve or maintain their health. They also help us understand social, political and economic forces at work related to the health status of people (Mercado & Magalhaes Bosi, 2007; Patton, 2005)

In this needs assessment, three types of stakeholders were consulted. One stakeholder group is PRMCH staff from the Central and Regional levels. A second group of stakeholders are representatives from collaborating organizations actively participating in boards and/or committees sponsored by PRMCH. A third group consulted consists of

participants of three MCH programs, namely the Home Visiting Program, Healthy Start and the Youth Health Promoters Project.

Several questions guided the collection of qualitative information in the needs assessment:

- What do stakeholders see as health-related issues affecting MCH populations?
- What are the emerging needs from the perspective of stakeholders?
- What are PRMCH major strengths and challenges in addressing the health and well being of population groups?

The qualitative information gathered in the needs assessment relied on five methods or data sources. These are:

1. **Health Dialogues.** A series of Health Dialogues were conducted to gather first-hand information on the experiences, knowledge and perceptions of the three types of stakeholders consulted. The structure of the health dialogues was flexible and informal; the atmosphere that permeated was one of mutual respect between the facilitators and the participants. A script or health dialogue guide was used to guide the discussion. The guide consisted of an introductory segment and several open-ended questions to allow participants to freely speak about their experiences, knowledge and concerns. The guides for PRMCH staff, members of committees, and members of Regional Boards contained questions on the problems and needs of each MCH general population group (infants, pregnant women, reproductive age women, children and adolescents) and strengths and challenges of their respective programs, committees/boards, and PRMCH. The guide for women participants in the Home Visiting and Healthy Start programs included questions about their infants and children's health and their experiences with health services. The guide for youth health promoters contained questions about problems affecting adolescents and their needs as adolescents and as health promoters.

A total of 24 health dialogues were carryout. 5 with PRMCH Central level staff; 4 with regional staff; 11 with PRMCH regional boards and committees; and 5 with target populations (mothers, pregnant women, and adolescents) that participate in PRMCH sponsored programs. Altogether 85 persons participated in the health dialogues.

The Health Dialogues were recorded and transcribed. These transcripts were then analyzed inductively and followed circulatory step procedures (the researcher goes back and forth through the steps). These analytic procedures were:

- Read through the transcripts and field notes several times (data immersion) to become intimately familiar with the content.
- Identified key issues, concepts and themes within the texts.
- Assigned codes (words or phrases to label ideas discovered in the texts) to the fragment of texts that represent themes
- Identified and examined the patterns (connections, similarities or contrasting points) emerging in themes across texts.

- Arrived at meanings and explanations (data interpretation) from a social and cultural perspective.

2. Individual interviews. Seven individual interviews were conducted in the needs assessment. Two informal interviews were undertaken with men who are the spouses of participants in the Home Visit and Healthy Start programs. Two interviews were conducted with participants in a PRMCH demonstration project in one Social Treatment Center of Juvenile Institutions. Key participant interviews were also conducted with three PRMCH program coordinators. All individual interviews were transcribed. The same procedures used to analyze the health dialogues were applied to the individual interviews.

3. Evaluation reports of PRMCH programs. Qualitative findings from evaluative reports of the Home Visiting, Healthy Start, and Youth Health Promoters programs were integrated into the needs assessment. These reports are: 1) The Effects of the Youth Health Promoters Project in Middle Schools of the Department of Education (2007); 2) Qualitative Responses to Evaluative Questionnaire of Youth Health Promoters (2008); 3) Evaluation of Healthy Start and Home Visiting Programs Annual Activity (2009); 4) Satisfaction Study of the Healthy Start Project Clients, 2007-2009.

4. Health issue-specific qualitative research. Information from the anthropological oriented study titled “Pregnancy and Motherhood: Cultural Perspectives of High School Pregnant Teens and Teen Mothers in the Bayamón Health Region (2010)” has been incorporated into the qualitative findings. This study presents an analysis of the cultural factors leading to teen pregnancy and the views and experiences of teens, which go through **pregnancy** and motherhood. The study also presents the views of school professionals (counselors and social workers) working with this population. The methods used to gather information were focus groups, two person interviews, key participant interviews, and individual interviews (narratives).

5. Youth Dialogues. Information obtained from a series of Youth Dialogues on teen pregnancy and relationships were also incorporated into the needs assessment. The youth dialogues were carried out between 2006 and 2008 in public middle and high schools.

Methods and Data Sources Used to Assess State Capacity

The PRMCH Program evaluated the ability of the existing system to provide and support needed health care and related services. There exists a diversity of programs and initiatives that tackle the problems and needs of the general MCH populations. Different techniques were used to collect information on programs, projects and initiatives that deal with issues pertaining to the general MCH population groups. Through informal telephone interviews, reports, internet information, and questionnaires, we identified the principal services and programs by levels of the pyramid. A list describing services provided to MCH population groups at every level of the MCH pyramid was developed (Figure II-37).

In order to perform a more comprehensive analysis of the PRMCH capacity, EMRSDS/SSDI Coordinator adapted the Capacity Needs Survey of the *Capacity Assessment for State Title V (CAST-5)* tools developed by the AMCHP and Johns Hopkins University Women's and Children's Health Policy Center. The purpose was to assess the infrastructure – building capacity within the MCH Program to enhance a quality MCH System.

Furthermore, to gather input from stakeholders, the EMRSDS/SSDI Coordinator prepared a survey adapting some questions contained in the System Capacity for Adolescent Health: Public Health Improvement Tool of the Association of Maternal and Child Health Programs and the State Adolescent Health Coordinators Network. This questionnaire helped identify system capacity according to the needs recognized through the MCH Health Regions.

The qualitative data obtained from health dialogues and individual interviews also highlight issues related to the system capacity. In discussing needs and concerns, participants generally pointed to the existence or non-existence of resources and/or services; spoke about medical providers and patient relations; shortages of physicians; transportation barriers and other systemic issues. On the other hand, PRMCH staff and members of the Regional Boards were asked to assess the strengths and challenges they face in their respective programs and/or boards.

e. Linkages between Assessment, Capacity, and Priorities

The three-phased framework used in the 2010 HNA enabled PRMCH to interconnect needs assessment, capacity assessment, and the selection of priorities. First, we collected and analyse quantitative and qualitative data for each population group (reproductive age women, pregnant women, infants, children and adolescents). Based on this information, we proceeded to examine the capacity of the system to meet the identified needs. The examination of the system capacity involved the identification of all activities, services and programs related to the needs. These activities, services and programs were then classified according to the MCH pyramid levels. These steps prepared the way for the selection of priorities. A broad list of potential priorities was developed and then narrowed according to established criteria that allowed us to make final decisions on the priorities.

f. Strengths and Weaknesses of the Needs Assessment Process

Traditionally, Puerto Rico's needs assessment focused almost exclusively on quantitative data gathered through surveillance, evaluation and epidemiological research studies among others. The 2010 HNA added the qualitative data gathering as an equally important dimension of the process of needs assessment to gain insights into the views and experiences of stakeholders in relation to health-related needs and the capability of the system in responding to the identified needs. Collecting both quantitative and qualitative data provides a more comprehensive picture of the health status, needs, barriers and the system capacity to guide the strategic planning.

PRMCH began to move from a deficit-oriented to a health promotion approach that focuses on positive outcomes to address the needs and improve the health status of MCH general population groups.

The long-track record of PRMCH collaborative mechanisms made possible the access to quantitative data from external sources. In fact, about 98% of the agencies, organizations and programs whom we sought data provided it.

Having an established structure through which different groups of stakeholders (health-related professionals and MCH populations) continuously participate (i.e. regional boards, program-related committees, participants/consumers committees and groups of volunteer youth health promoters) was critical in the needs assessment process. It was through this structure that the health dialogues were carried out to assess needs.

Engaging stakeholders, including PRMCH staff, in the various phases in the needs assessment process allowed PRMCH to gain insights into their experiences and views about health-related issues and how accessible services are. Gaining these insights permitted PRMCH ascertain what issues are most important for staff, collaborators, pregnant women, adolescents, mothers, and families. In other words, PRMCH is able to tell the story through the voices of the people that experience the health system either as beneficiaries (MCH populations) or as providers (especially front-line workers).

The commitment of PRMCH staff – both from Central and Regional levels - to contribute to the needs assessment, despite having a full slate of responsibilities proved to be one of the most invaluable strengths. They provided the EMRSDS team with data about their respective programs, willingly participated in health dialogues, and helped in the coordination of health dialogues with the Regional Boards and program-participants (MCH populations). Their participation in different internal and external coalitions, committees, boards, alliances, advisory groups and tasks forces proved to be extremely useful in accessing information about health issues and strategies used to address them.

Having an internal PRMCH multidisciplinary research team (EMRSDS) proved to be an asset to Title V in carrying out qualitative fieldwork, quantitative data gathering, and analysis in the needs assessment. This team not only gathered and pulled together the data and input from stakeholders but also was instrumental in leading the needs assessment process.

In spite of the abovementioned strengths, several limitations interfered with certain needs assessment processes. First, transitions in the Title V Director caused interruptions in the needs assessment processes. From late 2005 through 2009, PRMCH has had four directors. Each time a new director came on board, he or she focused on administrative issues or particular health issues of her or his interest. One former director began the needs assessment process which was later set aside by a new director that later left MCH. Meanwhile, the staff continued working on the process of gathering of information for the

needs assessment. The coming of the current director facilitated the continuation of the process without further interruptions.

PRMCH also faced delays in data collection processes for the needs assessment. To a large extent, delays are due to structural changes underway in the Puerto Rican government involving massive-layoffs. Personnel reduction in the PR government agencies resulted in loss of contact persons and established relationships that hindered our capacity to timely collect the data required to assess needs and evaluate system capacity.

Technological limitations also put a strain in the needs assessment process. Qualitative research requires the use of voice recorders but PRMCH has only one recorder available for which reason the cultural anthropologist shared her own recorder with other members of the Qualitative Workgroup. Considering the number of health dialogues that took place – which often times had to be scheduled the same day or the next day – having two voice recorders available was insufficient to perform the work. The voice recorder insufficiency provoked – what the cultural anthropologist calls – “a hectic pass around of recorders” among members of the Qualitative Workgroup. This situation points to the need to make available more voice recorders to facilitate qualitative data gathering. In addition, the computers used by some researchers are not performing well and frequently freeze. These computers are loaded with outdated programs such as Word 2000 that hinders capacity to perform research-related tasks.

Last, but not least, PRMCH overlooked to include community stakeholders in the process of narrowing potential need priorities (phase 3); although adult stakeholders provided insight of needs and capacity for their community thru a questionnaire, there was no participation of youth stakeholders. In the future, PRMCH must develop a plan to allow community stakeholders to participate in this phase of the needs assessment process.

g. Dissemination of the Needs Assessment Document

To disseminate the 2010 HNA, PRMCH will hold presentations of findings to target audiences. The target audiences are: 1) Local and state government officials; 2) Community agencies and organizations; 3) PRMCH Regional Boards; 4) PRMCH sponsored committees; 5) Professional groups from diverse fields; 6) MCH population groups including participants of the Home Visiting, Healthy Start and Youth Health Promoters programs. In addition, the Needs Assessment as part of Title V Block Grant Proposal is available to interested persons and agencies in the Central PRMCH and each Regional Office.

2. PARTNERSHIP BUILDING AND COLLABORATION EFFORTS

a. Collaboration Processes

In Puerto Rico, fairly satisfactory collaboration mechanisms – formal and informal - are in place among several public agencies and community sectors at the state, regional and local levels. PRMCH serves as a focal point for influencing the efforts of a broad range of agencies and programs working towards the social, mental and physical well being of the target populations. Formal agreements between the Department of Health and other state public agencies, local public health agencies, academic institutions, federally qualified health centers and tertiary health care facilities further enhance the capacity of the MCH/CSHCN programs to promote the health of the populations served.

Formal agreements are the extension of established laws and executive orders of the Governor, which mandate specific agencies and programs to sit together to understand how each other's roles and actions can lead to the coordination of certain types of services for the MCH population. There are also memorandums of understanding (MOU) among agencies and programs, which enhance the coordination of services. Other formal mechanisms, which contribute to the achievement of this goal, are interagency committees, task forces and coalitions, among others. Several of the laws, executive and administrative orders and committees require the participation of consumers.

Health-related actions could not be effective without concerted collaborative efforts with other programs and agencies. To effectively address health needs of the general MCH populations, PRMCH has established different types of collaborations. These are:

Education and Health Promotion. PRMCH has built links with health, social service, and education providers to disseminate information and educate particular MCH population groups and the general public through workshops, presentations, trainings, health fairs, and massive campaigns.

Professional Training. PRMCH has established collaborations to co-sponsor and/or participate in training targeted at professionals. This type of collaboration takes two forms. In the first place, PRMCH provides trainings to service providers from the education, social, and health fields on health issues. Secondly, other agencies provide trainings to PRMCH staff on a diversity of topics that enhance the work with targeted populations. In addition, PRMCH staff participates in professional trainings offered to larger audiences from diverse professional fields.

Committees. PRMCH supports the efforts of external programs and agencies through staff participation in task forces, committees, alliances, and community groups. Other agencies provide us support by having representation in committees and /or boards sponsored by PRMCH.

Monitoring and Research. There are collaborations to access data from a variety of agencies, programs and institutions. Collaborations are also established to conduct research-related activities.

The Table II-1 lists the institutions, agencies and programs that are working collaboratively – either through formal and informal agreements - with PRMCH to attend the needs of the general MCH population groups.

b. Stakeholder Involvement and Contribution to the Needs Assessment

A diversity of stakeholders of various competencies and /or experiences was consulted throughout the needs assessment process. Stakeholders involved included: a) health and human service providers that are close collaborators of PRMCH; b) Adolescents that participate in PRMCH sponsored youth programs and/or activities; c) pregnant women, parents and families that participate in the Home Visiting Program and Healthy Start Participants (Consumer) Committees; d) PRMCH staff from the Central and Regional levels. These stakeholders participated in the needs assessment process through a variety of activities that included health dialogues, program evaluation assessments, youth dialogues and research on specific health topics. The input provided by stakeholders was critical to achieve a comprehensive understanding of health-related issues, service needs and barriers, and system capacity. Stakeholders also provided recommendations regarding the actions that need to be taken to promote the health and well being of MCH populations. Very importantly, the input obtained from stakeholders served as the basis for the final stages in setting needs priorities and strategies. After all the information had been gathered and analyzed, PRMCH convened a group of stakeholders to work together in a two-day long consensus meeting to narrow potential priorities, assess resources available, and determine the best strategies to meet needs and/or problems. (Please see the qualitative methods/data sources and the selection of state priorities sections for detailed information about stakeholder involvement).

c. Results, strengths, and weaknesses of collaboration efforts

The 2010 HNA has been an on-going process built upon existing – formal and informal – collaborative efforts. The PRMCH has a long track record of working with other agencies and/or institutions that facilitated the gathering of both quantitative and qualitative data.

In the first place, PRMCH have established mechanisms to access databases and data from multiple sources to monitor MCH populations' health issues from diverse agencies and/or institutions. By insuring access to these data we are able to perform data linkages and the corresponding analysis that help us to assess needs. Among the participant agencies and/or institutions that provide information, access or sharing data on a regular basis are: Office of Informatics and Advanced Technology (OITA), WIC program, Birth Defects Surveillance and Folic Acid Campaign, Medical Assistance Program (Medicaid), Demographic Registry Office, Immunization Program, Newborn Screening for Hereditary Diseases, Administration of Health Insurance (ASES) and Insurance Commissioner Office (OCS) on

a regular basis. Other collaborative efforts include those established with external agencies and/or institutions to conduct surveillances and investigations. Among agencies that collaborate are hospitals that participate in the PR Maternal and Infant Health Survey (PRAMS-like surveillance database), the public school system, Head Start and others.

An important collaboration mechanism are the seven PRMCH Regional Boards, composed of representatives from government and non-government entities that meet regularly to share information about their respective programs, discuss issues related to maternal, child and adolescent health, and solve urgent particular health-related situations of individuals and/or families. Regional Boards also identify gaps in knowledge and share resources to coordinate activities to educate the public on how to lead healthy lifestyles. Regional Boards members also engaged in the needs assessment by participating in the health dialogues to assess target populations needs/problems and the capacity of the health system to meet those needs. They also filled out the Health Indicators Questionnaire to identify needs priorities, agencies/organizations, and strategies to address them.

Another mechanism relates to the variety of PRMCH sponsored committees - composed of diverse stakeholders with various competencies and capabilities - such as the Healthy Start Consortium, Breastfeeding Committee, and the Fetal and Infant Mortality Review Committee. Committees either address a particular health-related issue or multiple health issues affecting specific MCH populations. Members of the some committees also engaged in the health dialogues to assess MCH population needs and system capacity.

PRMCH central and regional level staffs who participate in external committees, advisory groups, coalitions and/or alliances used these relationships to obtain information related to the needs of MCH populations and the system capacity.

Most importantly, both intra program (within PRMCH) and inter agency collaborative efforts made possible consumer collaboration in the 2010 HNA. For instance, collaborative efforts with the Department of Education led to gather input from adolescents through youth dialogues and interviews in health research. Actually, PRMCH has groups of highly motivated adolescent volunteers - called Youth Health Promoters - in public middle schools in all health regions that take on the charge of promoting healthy lifestyles among their peers. Youth Health promoters provided information through evaluation assessments and a health dialogue on issues pertaining to adolescent health needs. Student pregnant teens and mothers participated in the PRMCH qualitative study on their experiences and cultural perceptions. Pregnant women, reproductive age women, parents and families of infants and children became involve in the needs assessment process through the Home Visiting and Healthy Start programs. These populations gave input through evaluation assessments and participation in health dialogues.

In spite of the above mentioned strengths, there are limitations in regard to collaborative efforts. The following factors adversely affect collaborations:

- Rigid structures of partner agencies hamper the fluidity of action mechanisms.
- Lack of continuity when formal agreements expire or administrative changes take place.

- Personnel turnover affects the stability of informal collaborations.
- Under-representation of local (municipal) agencies in the Regional Boards.
- Municipal agencies are a parallel network of services that is under-coordinated with the State MCH Division.
- Little or no representation from community-base organizations in the Regional Boards.

3. STRENGTHS AND NEEDS OF THE MATERNAL AND CHILD HEALTH POPULATION GROUPS AND DESIRED OUTCOMES

This section presents the findings from qualitative and quantitative gathering methods about the health status, needs and problems faced by the general MCH population groups in accessing and utilizing health-related services.

Strengths and Needs of the General MCH Populations: Quantitative Findings

This section describes and analyzes the quantitative data about the needs of MCH populations. The data presented has been divided into two sub-sections. First, data from the on-going needs assessment process is presented. Second, data obtained from a health indicator survey conducted among stakeholders is described.

A. Women in reproductive age, Pregnant Women and Infants

a. Reproductive age women (10 to 49 years)

Sociodemography

According to the Puerto Rico Community Survey in 2007 the number of women in their reproductive age (WRA 10-49 years) was 1,131,864. This figure represents 28.7% of the total population in Puerto Rico. Among all WRA, 26.0% were in the age range 10-19, 37.2% were 20-34 and 36.7% were 35 or older (Figure II-1).

According to the survey, 46% of the women were married in 2007. However, 37.2% of families with children were headed by a female householder. This represents an increase (37.8%) over the share of female-headed families with children, in 2000 (27%). By contrast, in the U.S. the proportion of female-headed families increased from 22% in 2000 to 24% in 2007.

In 2008, WRA holding the GIP numbered 423,391 in PR. This figure represents 37.4% of all WRA reported in the Puerto Rico Community Survey in 2007.

Educational attainment is a strong determinant of economic well being. According to the Puerto Rico Community Survey in 2007, PR women have a higher number of years of formal education than men (68.1% vs. 64.3%, respectively).

Preconception Care

Preconception care is recognized as a critical component of health care for women of reproductive age. The main goal of preconception care is to provide health promotion, screening and interventions for women of reproductive age to reduce risk factors that might affect future pregnancies. According to the Centers for Disease Control and Prevention (CDC), preconception care is a set of interventions that identify and modify biomedical,

behavioral, and social risks to a woman's health and future pregnancies. It includes both prevention and management, emphasizing health issues that require action before conception or very early in pregnancy for maximal impact. The target population for preconception care is women of reproductive age, although men are also targeted by several components of preconception care.

Following, there is data of health status, physical activity; screening tests and acid folic consumption, from different sources of information, that briefly depict how women in Puerto Rico manage preconception care in some areas.

According to BRFSS 2008, 53.1% of the participants were female, where 68% of them were between the ages of 18 to 54 years old. Approximately 64% of women reported their general health as excellent, very good or good, whereas 36.5% reported their general health as fair or poor. Around 46% of women reported participating in any physical activity during the past month.

It is known that the maternal oral health has a great influence in the oral health of the child. On top of that, dental caries are a bacteriological disease that can be transmitted; if the mother has a good oral health there is a lower risk of transmission to her child. BRFSS 2008 reports that 78.5% of women visited the dentist clinic within the past year for any reason.

A Pap smear identifies cervical and/or vaginal cells that are cancerous or could be potentially pre-cancerous. According to BRFSS 2008, 47% women between 18 to 24 years, 74.3% between 25 to 34 years, 88% between 35 to 44 years and 85.5% between 45 to 54 years had a Pap test within the past three years. According to ASES, during 2009 approximately 5% of women from 10 to 49 years and insured by GIP had a Pap test.

A mammography is a specific type of imaging that uses a low-dose x-ray system to examine breasts. It is used to aid in the early detection and diagnosis of breast diseases in women. According to BRFSS 2008, 74.4% of women between the ages of 40 to 49 years had a mammogram within the past two years. According to ASES, during 2009 approximately 3% of women from 10 to 49 years and insured by GIP have a routine mammography.

According to the Puerto Rico Immunization Program, as of April 2010, of all the MMR shots (measles, mumps and rubella) administered, about 49% of them were administered to women between 10 to 49 years old. For this same period, 58% of influenza shots, 52% of H1N1 shots, 92% of HPV shots and 48% of Hepatitis B shots, were in women between 10 to 49 years old.

The literature suggests that a dairy consumption of 400 mcg of folic acid in women between 10 to 50 years may help to prevent up to 70% of Neural Tube Defects (NTDs).

According to ESMIPR 2008, among surveyed women, 65.5% did not consume folic acid or multivitamins during the month prior to conception. This behavior is associated with an increased risk of bearing a baby affected with NTDs and other anomalies such as cleft lip/palate, transverse limb defects and conotruncal heart defects.

The PR BRFSS also queried surveyed persons regarding folic acid knowledge and consumption. The Folic Acid Campaign efforts have helped increased significantly the knowledge about folic acid vitamin benefits among the reproductive age women in PR. However it has not been as effective increasing folic acid consumption. All health care professionals should be aware on the PR Department of Health Public Policy on folic acid use, and they should help promote the benefits of the vitamin in the prevention of birth defects and some chronic illnesses. It is imperative to increase collaborative efforts to promote this healthy habit in order to improve the health of this population.

In 2008, with the objective of assessing trends in NTD prevalence at birth and prevalence of knowledge and consumption of folic acid supplements in Puerto Rico (PR), data from the PR Birth Defect Surveillance System (BDSS) and vital statistics records were used to calculate total annual NTD prevalence at birth as the number of spina bifida or anencephaly cases (including live births, fetal deaths, stillbirths, spontaneous abortions, and elective terminations) per year, multiplied by 10,000 and then divided by the number of live births for each year. To assess folic acid knowledge and daily folic acid consumption among non pregnant women aged 18-44 years in Puerto Rico, data were collected from the BRFSS surveys administered in 1997-1998, 2000, 2002-2004, and 2006. Statistical estimates were weighted to reflect the total population of women aged 18-44 years in PR. Differences in data points were considered statistically significant at $p < 0.05$ by chi-square test. The annual birth prevalence of NTDs (i.e., bifid spine and anencephaly) in PR declined significantly ($p < 0.05$) from 14.7 per 10,000 live births in 1996 to 5.3 per 10,000 in 2003. The prevalence of NTDs did not change significantly in 2004 (7.8 per 10,000) or 2005 (8.7 per 10,000). During a similar period, the estimated prevalence of folic acid supplement consumption among non pregnant women aged 18-44 years increased significantly from 20.2% in 1997 to 30.9% in 2003, then decreased to 24.8% in 2006. Similarly, the estimated prevalence of knowledge of folic acid increased from 22.4% in 1997 to 72.0% in 2003, and then decreased to 56.5% in 2006 and went up to 61.6% in 2008 ($p = 0.08$). The end of the decline in NTD birth prevalence in PR in recent years is a cause for concern. The decline from 1996 to 2003 likely was aided by a campaign urging women to consume folic acid supplements and by introduction of mandatory folic acid fortification of U.S. flour and cereal grain products in 1998. Since 1994, the PR campaign to increase the percentage of women of childbearing age who consume folic acid supplements has resulted in some success. For example, the 24.8% of Puerto Rican women who reported folic acid supplement consumption in 2006 was nearly double the 13.1% prevalence reported by Hispanic women in the mainland United States during 2001-2002. However, despite all the measures taken by the BDSS Prevention Campaign, only approximately one fourth of women of childbearing age in PR consume a vitamin containing folic acid daily, suggesting that other factors might affect behavior. Additional measures directed at understanding and identifying barriers for taking the vitamin and to help promote folic acid awareness and

consumption among all non pregnant Puerto Rican women of childbearing age are warranted.

Another study (2007) was developed with the objective of comparing the folic acid knowledge and consumption between mothers with NTD affected pregnancies and mothers from the general population. Data from PR BDSS Genetic Counselor interviews to mothers with birth defects affected pregnancies were used to determine the folic acid consumption and knowledge of these mothers. Folic acid use was determined assessing the percent of mothers that reported using folic acid at least 3 months prior the NTD affected pregnancy. The folic acid knowledge in this population was assessed determining the percent of mothers that knew (at the moment of the interview) that folic acid helps prevent birth defects. A total of 215 mothers with NTD affected pregnancies were contacted and interviewed by the genetic counselor during 1999-2005, which accounts for a response rate of 68.3%. For this period, just 14.9% of mothers with NTD affected pregnancies reported using folic acid at least 3 months before the affected pregnancy, despite the fact that 51.3% of the mothers knew that folic acid helped prevent birth defects. On average, the folic acid consumption reported by the mothers with NTD affected pregnancies, in the three months prior to their pregnancy, was less than 50% the consumption reported by the reproductive age woman of the general population. Since 2003, these mothers also reported less knowledge on the benefits of folic acid when compared to women from the general population. Regardless of the increase in folic acid use and knowledge in reproductive age women of the general population, the folic acid use in PR is low, and even lower in mothers with NTD affected pregnancies. Therefore, we still need to stress the importance of folic acid use during the reproductive age.

In conclusion, data here stated suggest that there is an increase of awareness of health during the preconception period in women in reproductive age. However, to achieve optimum results, it is important to continue to promote, educate and inform this population about the benefits of preconception care.

Family Planning

According to the World Health Organization, family planning is the planning of when to have children, and the use of birth control and other techniques to implement such plans. Family planning is sometimes used as a synonym for the use of birth control, though it often includes more. It is most usually applied to a female-male couple who wish to limit the number of children they have and/or to control the timing of pregnancy (also known as spacing children).

According to PROFAMILIA Program during 2009, 44,060 participants received different types of birth control methods. Most of them (79.6%) received oral contraceptives, 8.4% Ortho Evra patches, 5.8% condoms (5.6% masculine and 0.15% feminine), 3.1% Depo Provera Shots, 2.6% Plan B pill, 0.34% Nuvaring pill and 0.19% IUD. PROFAMILIA has several projects oriented to adolescents (14 to 18 years old). The Project Wait is aimed at educating adolescents in terms of pregnancy prevention, sexual health and STD's so they

become facilitators of these information to peers in schools. Therefore, after capacitating 20 participants, around 1,090 adolescents were part of 15 activities that were facilitated by their peers. The Project Wait provides services of HIV/AIDS prevention to people between 13 to 21 years old that are school dropouts in five municipalities of Puerto Rico (San Germán, Lajas, Guánica, Cabo Rojo and Mayagüez). A total of 2,683 participants received services from this project in 2009. Finally, in 2009 around 20,000 participants were part of at least one of the many counseling/educative workshops of PROFAMILIA.

Other type of family planning that is commonly used among the Puerto Ricans is sterilization. According to data from ASES for fiscal year 2008-2009 approximately 16.3% of women and 0.10% of men were sterilized.

Findings from ESMIPR 2008 revealed that 65.5% of surveyed mothers did not plan the pregnancy. This figure represents a very wide gap between the goals of Healthy People 2010 that has established that 70% of all pregnancies should be planned. But even worse, 5.8% of the surveyed mothers said that they did not want to get pregnant ever or never (Figure II-2).

Family planning plays a key role in many aspects of a healthy life. If a pregnancy is planned, preconception care (folic acid consumption, oral heal, screenings, among others) is taken under consideration, decreasing negative pregnancy outcomes. If an infant is expected, abuse and neglect and domestic violence will also decrease.

Lifestyle

Women exposed to unhealthy behaviors such as smoking, drinking, domestic violence, among others, are at increased risk of conditions and outcomes that can conduct to complications including death.

The 2008 BRFSS data reports that 4.6% of women smoke everyday, 3.4% smoke some days, 12.5% were former smokers and 79.6% never smoke. Around 19% of the women reported to have at least one alcohol drink within the past 30 days, 2.4% reported having more than one drink per day and 5.1% reported having four or more drinks on one occasion.

Sexually transmitted diseases (STDs) are infections acquired by sexual contact. The risk of catching any STD depends on sex, age and sexual practices, as well as on the sexual practices and lifestyles of the partners. At all ages, women are more likely than men to have severe STD complications, such as infertility. In teenage girls and young adult women, the cervix is made up of constantly changing cells. These unstable cells make the cervix more vulnerable to certain sexually transmitted organisms. In 2009, the STDs Surveillance System reported 7,312 cases of chlamydia for a rate of 184.7 cases per 100,000 inhabitants. Over 85% of all cases were females compared to only 15% males. It is important to highlight that 97.9% of all infected women were between 15 and 44 years of

age. On the other hand, only 230 cases of gonorrhea were reported for a rate of 5.8 per 100,000 persons. The prevalence of infected females with gonorrhea was higher, 52.2% compared to 47.8% for males. Of all infected women with gonorrhea, 95% were in the age group 15-44 years old.

Domestic violence is an alarming and complex public health problem in Puerto Rico. This statement is supported by selected sociodemographic data, MCH health indicators and data from the Police Department. This public health problem is a concern for government officials, legislators, women's advocacy groups, health professionals and the public at large. In fact, the issue is frequently brought to public attention through mass media communications in headline news. However, in spite of the well-documented needs and awareness regarding the problem, programs and services for addressing this issue are fragmented. The current system for screening, routinely assessing, preventing, referring and directly intervening in cases of domestic violence is quite deficient.

During the decades leading to the turn of the century, the issue of domestic violence against women by intimate partners has changed from being considered a private or taboo matter to being recognized as a large public health problem with underlying causes and consequences not only for the victims, but also for the society in general. This is a very complex public health problem that requires the partnership of a variety of public and private entities in developing strategies for improving systems of care to be effective in the prevention, identification, and management of victims as well as in developing public policy.

Since the enactment of the law for the "Prevention and Intervention Against Domestic Violence", this issue has been brought into public attention (Law #54 of August 15, 1989). There has been an escalating trend of domestic violence reports to the Police Department since 1988. The number of incidents reported from 2007 to 2008 increased 18.3%, as well, the request for protective orders increased by 11%.

In analyzing 2009 data collected by the Police, 81% of the incidents reported were in women, where 58.3% were 20 to 34 years, 8.4% were less than 20 years and 33.2% were 35 years or more. For each male victim of domestic violence there were 4 female victims. However, most of the offenders are males (78%) and most of them are 20 to 34 years old (57.6%). In 2009 the Police Department reported 18 cases of death due to domestic violence, where 94% of the victims were females, 39% victims were killed with a fire gun, 39% with a sharp weapon, 17% with other weapon and 6% with physical strength.

According to data from fiscal year 2008-2009 offered by the Sexual Assault Victim Office (CAVV), a total of 622 women from 10 to 44 years were served in the San Juan Center, where most of the cases (56%) were adolescents 10 to 19 years of age.

Morbidity

During the reproductive years women develop certain conditions that could be detrimental during the pregnancy period. Hence the importance of preconceptive care, which may prevent these conditions from happening or maintain them at bay in case they have already developed.

BRFFS 2008 reports that 11.6% of women were told by a doctor that they had diabetes. In terms of cardiovascular disease, 3.7% were told they had a heart attack, 7.9% had angina or coronary heart disease and 1.7% had a stroke. Approximately 7% of the women were told they currently had asthma.

The PR Department of Health has several surveillances systems that monitor different conditions across the Island. The Cancer Registry and the Puerto Rico Asthma Surveillance System are examples of these systems.

In an analysis from the Puerto Rico Asthma Surveillance System from the Department of Health, a disparity in the prevalence of asthma for 2007 was evident, where women had a higher prevalence (8%) than men (3.9%). In terms of visits to the emergency room (ER) because of asthma, women with government insurance (344.55/100,000 reclamations) visited more the ER than those with a private insurance (100.79/100,000 reclamations). Furthermore, women in general visited ER more often for asthma than man.

According to the Puerto Rico Cancer Registry of the Department Health, the incidence (2003) of the top three types of cancer in women were breast cancer (66.3/100,000), colon and rectum cancer (26.96/100,000) and corpus and uterus cancer (15.47/100,000).

In addition, as reported by BRFFS 2008, 40.8% of the women were neither overweight nor obese ($BMI < 24.9 \text{ kg/m}^2$), 33.4% were overweight ($BMI = 25 - 29.9 \text{ kg/m}^2$) and 25.8% were obese ($BMI = 30 - 99.8 \text{ kg/m}^2$).

In a consultation made to the principal health insurances of Puerto Rico (private and governmental), the first five causes of medical visits, ambulatory services, emergency services and hospitalization for 2008-2009 in women of reproductive age were obtained. Following are the highlights by type of service and stratified by age.

In general, the main cause for a visit to a physician's office in women of reproductive age was because of pregnancy related symptoms (29.9%). However, the five main conditions that required a visits to a doctor in 2009 were inflammatory disease of cervix, vagina and vulva (5.3%), other symptoms involving abdomen and pelvis (5%), disorders of menstruation and other abnormal bleeding from female genital tract (4.7%), essential hypertension (4.3%) and acute upper respiratory infections of multiple or unspecified sites (4.3%). Adolescents (10 to 19 years) visit the physician more frequently because of pregnancy related symptoms (30.3%), whereas the main conditions for a visit were acute

upper respiratory infections of multiple or unspecified sites (7.6%), other symptoms involving abdomen and pelvis (4.8%), viral and chlamydial infection in conditions classified elsewhere and of unspecified site (4.6%), disorders of retraction and accommodation (3.2%) and other disorders of urethra and urinary tract (2.6%). Women 20 to 49 years old often visit a physician also because of pregnancy related symptoms (29.7%), but other main reasons for these visits were inflammatory disease of cervix, vagina and vulva (6.4%), essential hypertension (5.4%), disorders of menstruation and other abnormal bleeding from female genital tract (5.2%), other symptoms involving abdomen and pelvis (5.0%) and pain and other symptoms associated with female genital organs (4.4%).

Ambulatory services such as pregnancy related symptoms (16.7%), acquired hypothyroidism (8.9%), essential hypertension (8.1%), disorders of lipid metabolism (6.3%) and disorder of menstruation and other abnormal bleeding from female genital tract (6.3%) were the most prevalent among women of reproductive age. Ambulatory services because of pregnancy related symptoms were the most prevalent among adolescents (16.5%) as well as for women 20 years or older (16.9%). However, services for general symptoms (7.0%), other symptoms involving abdomen and pelvis (6.0%), acquired hypothyroidism (5.6%) and immunization (5.5%) were most prevalent in adolescents, whereas acquired hypothyroidism (9.5%), essential hypertension (9.3%), special investigations and examinations (7.2%) and disorders of lipid metabolism (6.8%) were the most prevalent ambulatory services in women 20 years and older.

Most of the frequent use of emergency services among women of reproductive age were because of other symptoms involving abdomen and pelvis (11.6%), other non-infective gastro-enteritis and colitis (9.4%), acute upper respiratory infections of multiple or unspecified sites (7.9%), injury, other and unspecified (7.7%) and viral and chlamydial infection in conditions classified elsewhere and of unspecified site (6.5%). When stratified by age group, other symptoms involving abdomen and pelvis (10.9%), other non-infective gastro-enteritis and colitis (10.3%), injury, other and unspecified (9.7%), acute upper respiratory infections of multiple or unspecified sites (9.1%) and viral and chlamydial infections in conditions classified elsewhere and of unspecified site (8.2%) were the most prevalent reasons for emergency services among adolescents (10 to 19 years), whereas other symptoms involving abdomen and pelvis (11.8%), other non-infective gastro-enteritis and colitis (9.0%), acute upper respiratory infections of multiple or unspecified sites (7.6%), other and unspecified disorders of back (7.4%) and injury, other and unspecified (7.1%) in women 20 years or older.

Aside from being hospitalized because of pregnancy related issues (77.0%), women of reproductive age were mainly hospitalized during 2008-2009 because of asthma (4.8%), cholelithiasis (4.3%), uterine leiomyoma (3.3%), other cellulitis and abscess (2.2%) and affective psychoses (1.5%). Adolescents were mainly hospitalized because of asthma (2.8%), acute appendicitis (2.5%), other non-infective gastro-enteritis and colitis (2.4%), other cellulites and abscess (1.8%) and gastritis and duodenitis (1.8%). In addition, 75.0%

of the adolescents were hospitalized due to pregnancy related symptoms. On the other hand, women of 20 to 49 years were hospitalized because of cholelithiasis (5.3%), asthma (5.3%), uterine leiomyoma (4.2%), other cellulitis and abscess (2.3%) and disorders of menstruation and other abnormal bleeding from female genital tract (1.9%). About 78% of women of this age were also hospitalized because of pregnancy related issues.

Finally, the most prevalent mental conditions in adolescents (10 to 19 years) are hyperkinetic syndrome of childhood (30.3%), affective psychoses (25.8%), adjustment reaction (12.6%), neurotic disorders (11.0%) and depressive disorder, not elsewhere classified (6.8%), whereas in women 20 to 49 years old the most prevalent mental conditions are affective psychoses (58.9%), neurotic disorders (19.0%), adjustment reaction (7.7%), depressive disorder, not elsewhere classified (5.7%) and special symptoms or syndromes not elsewhere classified (2.7%).

Mortality

According to 2006 Vital Statistics the mortality rate for women of reproductive age was 80.7 per 100,000 women. The first causes of death were neoplasm (22.7%), disease of the circulatory system (14.8%), certain infections and parasite disease (14.6%), disease of the respiratory system (8.5%) and unintentional injuries (8.1%).

The mortality rate in female adolescents (10 to 19 years) was 17.4 per 100,000 women in 2006. The main causes of death in this group were unintentional injuries (17.6%), disease of the circulatory system (13.7%), neoplasm and disease of the nervous system (11.8%) and disease of the respiratory disease (9.8%). On the other hand, the mortality rate in women between 20 to 49 years of age was 103 per 100,000 women for the same year. The principal causes of death were neoplasm (23.4%), disease of the circulatory system (14.8%), certain infections and parasite disease (14.6%), disease of the respiratory system (8.5%) and unintentional injuries (8.1%).

From these data it is evident that adolescents die from different causes than women 20 years or older. As a matter of fact most of the adolescents deaths were in a car accident, while neoplasm, particularly breast and colon neoplasm, was the main cause of death in women 20 years or older.

The Cancer Registry of Puerto Rico reports that the three types of cancer with a higher mortality in women were breast cancer (16.9/100,000), colon and rectum cancer (12.6/100,000) and lung and bronchus (10.4/100,000).

The Puerto Rico Asthma Surveillance System analyzed asthma mortality in women in reproductive age during 1999 to 2004. Findings report that approximately 2 of every 100,000 women died of asthma, however, this rate decreased significantly ($p < 0.05$) by 2004 (0.5/100,000).

b. Pregnant Women

Sociodemography

A total of 48,744 live births were reported in 2006. An analysis of the mother's health insurance plan at the time of birth revealed that 65% had the government insurance plan (GIP), 33.6% a private health plan and 1.3% had another source of payment or none. It is important to highlight that 95.2% of mothers under 14, 95% of 15-17 and 93% of 18-19 years old had the GIP.

Findings of the ESMIPR 2008 revealed among those mothers who reported their annual family income, 45.7% had an income less than \$10,000; 21% \$10,000-\$19,999; 18.4% \$20,000-\$39,999 and only 15.0% reported an annual income higher than \$40,000. The average number of family members depending on that family income was four. Fewer than 4 in 10 surveyed mothers (42.1%) reported that they were employed outside the home.

The proportion of women who had not completed 12 years of education at the time of birth is unacceptable. Even though the proportion of women without a high school diploma is decreasing, in 2006 almost 1 of 5 (21.2%) of mothers who had a live birth had not completed high school. Pregnancy is the leading cause of school desertion in the Island. As reported by the Department of Education for school year 2006-2007, forty three (43) students dropped out of school because of pregnancy.

Civil status is a variable that affects reproductive behavior and birth outcomes. Unmarried women are at higher risk of poor birth outcomes. In Puerto Rico, the increasing trend of the proportion of infants born to unwed mothers is worrisome. In 1997, 45.8% of children were born to unwed women, compared to 58.1% in 2006, which is a 27% increase. Nearly 8 of every 10 adolescent mothers (83.2% in 2006) were unwed.

To represent graphically the structure of age and sex, a population pyramid is used (Figure II-3). The bell shape that represents the population of Puerto Rico, corresponds to a regressive population (the number of deaths is similar to the number of births) and starts aging (total birth and deaths starts to decrease). The Island is showing a slow population growth with a smaller proportion in the younger inhabitants. When comparing the Puerto Rico 1990 population with 2005 decrease is observed in the younger groups and an increase in the older groups.

An analysis of the number of live births and the crude birth rate was conducted for the period 1990-2006. The crude birth rate was 18.9/1,000 persons in 1990, declining significantly ($p < 0.05$) to only 12.4/1,000 inhabitants in 2006. According to the Average Annual Percent Change (AAPC), birth rates are significantly decreasing by 2.5% as Figure II-4 clearly illustrates the fall in the trend of the crude birth rate in the Island. On the other hand, there was a significant birth increase in 1995 among adolescents until 1997 (AAPC = 8.2%), while in women 20 to 49 years old the birth rate continues to decrease by

2.3%. One of the possible explanations for this increase is the implementation of the Health Care Reform in Puerto Rico during the early 90's. Birth control methods were not that accessible to adolescents once Health Care Reform was implemented and as a consequence birth rates increased dramatically (Figure II-5). However, as observed in Figure II-5, birth rate in adolescents is decreasing by 3.7% since 1998 until 2006. It is important to highlight that birth rates are decreasing for all age groups.

A long-term decline in the total fertility rates has been observed in Puerto Rico since second half of the XIX century. In 1950, this rate was 5.2 births per women. By 1970, it had fallen to 3.2 births per women, and by 2000 it had dropped to 1.9 births per women. This level of fertility is slightly lower than the rate in U.S. as a whole—2.1 births per women—and substantially lower than the rate for women of PR descent, who had a rate of 2.6 births per woman in 2000. Since 2000 the total fertility rate was below the replacement level. For 2006, PR reported 1.7 births per women 10 -49 years old. Several measures were implemented in family planning, such as sterilization and the use of contraceptives, which affect this rate. Further, the time spent getting higher education and the female labor participation has negative impact on fertility. The literature mentions these issues as the result of the “demographic-economic paradox”. There have been other possible explanations for the general decline in birth rates. For one, the increase of urbanization in the Island is considered one cause. In recent times, residents of urban areas tend to have fewer children than people in rural areas. Cities tend to have higher property prices, making a large family more expensive. Changes in contraception are also an important cause, and one that has seen dramatic changes in the last few generations. A widespread acceptance of contraception in the developed world is a large factor in decreased fertility levels. Greater access to contraception and abortion, and greater proclivity of women to use them also has reduced rates.

Prenatal Health

In Puerto Rico there is an excess of morbidity and mortality among Puerto Rican women and infants residing in the Island. This is so not only when they are compared with white American women, but also with women of Puerto Rican descent residing in the US mainland. This situation may be the result of personal as well as health care system characteristics. Personal characteristics include age, educational attainment, marital status, socioeconomic conditions, unhealthy and healthy seeking behavior, pre-pregnancy and obstetric conditions. There are several indicators (i.e. congenital syphilis) that suggest an inappropriate implementation of current standards of quality prenatal care. Similarly, the escalating rate of cesarean sections and other perinatal clinical practices negatively impact the maternal and newborn health.

Vital statistics data for Puerto Rico in 2006 reported that approximately 1 in 5 pregnant women initiated prenatal care after the first trimester or had no prenatal care at all. This group of women is more likely to have poor maternal and birth outcomes. The barriers for the initiation of prenatal care in the first trimester are multifactorial. Reducing these barriers should be a concern of all the stakeholders of the health services system and social

sectors related to the promotion of health and the prevention of risk factors among pregnant women and their babies.

Figure II-6 shows almost a plateau in the first trimester admission until 2004. However, the new birth certificate was implemented during 2005 causing some changes in the way certain information was completed. Trimester of admission to prenatal care was one of these changes, causing a lot of missing data and therefore significantly decreasing to 71.6% ($p<0.05$). Nevertheless, in 2006 first trimester admission significantly increased to 82% ($p<0.05$). It is important to mention that the first trimester admission rate has increased only by 0.7% during a 17 year period (70.8% in 1990 to 82% in 2006).

The Kotelchuck Index is an indicator frequently used to determine the adequacy of the prenatal care. It is calculated using three distinct fields: the date of the last menstrual period, the number of prenatal visits (and when they started), and the date of birth. Currently, the MCH Program uses data provided in the birth certificate to calculate the Kotelchuck index. During 2006, the Kotelchuck Index was adequate or adequate plus in 81.5% (women of reproductive age). The percent of women with a live birth during 2006 that had an adequate or adequate plus prenatal care according to the Kotelchuck Index increased with age. It was 62.9% for the 10 to 14 years age group, 73.4% for those 15 to 19 years of age, 82.9% for those 20 to 34 years and 87.8% for those 35 years or more. Pregnant women in about 77% of all municipalities ($n=55$) received adequate or adequate plus prenatal care.

The Healthy Start Program completed a study during 2005-2006, where the participants were compared to a control group of non participants in the same population in a series of indicators included in the IIMIHS (number of prenatal care, visits, birth and pregnancy outcomes and infant mortality rates). One was conducted in 2001 comparing birth outcomes of HVP participants ($n=1,052$) with a no-treatment equivalent control group ($n=1,052$) matched by age, educational level and source of payment for health services. The findings suggest that in 2001 the HVP participants had more high-risk characteristics that contribute to poor pregnancy outcomes than non-participants. The proportion of participants who did not live with a partner was greater than the controls (26.0% vs. 22.7%; $0.05<p<0.1$). Prior abortions or fetal deaths were greater in the HVP group than in controls (11.9% vs. 11.0%). This study reported that first trimester initiation of prenatal care was equal for participants and controls (72.2%). There was no significant difference in preterm births between the groups. The average number of prenatal visits (10.16 vs. 10.04). The proportion of very low weight birth was significantly greater in the HVP group than in the controls (2.1% vs. 0.7%; $p<0.05$), contrasting with the first study. It is important to mention that there were no significant differences between the two groups when this variable was categorized in two groups (adequate $\geq 2,500g$ and inadequate $<2,500g$). HVP participants had significantly better prenatal care in the Adequate Plus category of the Kotelchuck Index than controls (32.2% vs. 27.8%; $p<0.05$). Additionally, the proportion of participants who had inadequate prenatal care was lower than the control group (14.3% vs. 16.8%). In summary, the findings of the present study suggest that prenatal care and birth outcomes in

participants and controls are similar, although participants begin their pregnancy with more risk factors than the controls. Based on that information, we can infer that the HVP is helping our participants achieve a more reasonable prenatal care improving their chances for a better birth outcome. The Healthy Start participants had more high-risk characteristics that contribute to poor pregnancy outcomes than non-participants, nevertheless, the findings of the present study suggest that prenatal care and birth outcomes in participants and controls are similar. Therefore, is important to continue with the intervention of the Healthy Start Project, in addition, the study shows that the participants of the Healthy Start Program do have significant more low weight births in comparison with the control group.

Comprehensive prenatal care must include screening for a variety of unhealthy behaviors in which a significant proportion of pregnant women may be involved, and counseling or anticipatory guidance according to identified risks. However, our most recent study, the ESMIPR, shows a wide window to improving comprehensive antenatal care on this regards. Surveyed women told us that they received orientation on several queried topics by physicians, nurses, nutritionists, health educators, social workers and others.

Nevertheless the frequency of the orientation and anticipatory guidance varied among providers and topics. The proportion of pregnant women who received orientation by her medical provider fluctuated between 35% and 82.1% according to the topics. It is important to underscore that the medical provider comes in contact with expectant women on an average of 10 times before delivery. But unfortunately these opportunities to promote healthy behaviors and prevent associated complications during pregnancy are lost. Only 63.9% of pregnant women received orientation on preventing premature births, 72.3% on smoking, 72.3% on alcohol consumption, 70.3% on illicit drug use, 81.0% on the effect of non-prescribed medications, 42.7% on physical abuse by her partner, 91.2% on folic acid consumption during pregnancy, 90.7% on the importance of breastfeeding, 74.1% on the importance of the postpartum visit, 93.8% on the importance of proper nutrition and only 68.5% were counseled regarding the proper position to lay her baby to sleep. On the other hand, the orientation provided by nurses hovered between 10.9% and 34.3%; nutritionists between 5.2% and 46.1%; health educators between 2.6% and 13.0%; and social workers between 0.4% and 8.5%. At this point it is important to underscore that not all pregnant women in PR are fortunate enough to come in contact with health educators, social workers or nutritionists in the current health care system based on a managed care model.

Maternal morbidity encompasses physical and psychological conditions resulting from or aggravated by pregnancy that have an adverse effect on the woman's health. Maternal morbidity ranges from mild to severe and can include complications and conditions associated with any pregnancy outcome. Extending maternal health surveillance to include identifying and reviewing pregnancy complications and factors associated with them has the potential to improve maternal health by providing information to influence the delivery of health services and health policy.

Pregnant women experience hormonal changes that contribute to the occurrence of certain oral diseases such as gingivitis or periodontitis. In addition, literature reports that pregnant women with an oral disease are at greater risk of premature or low birth weight infants. According to ESMIPR 2008, only 33.6% of expectant mothers contacted an oral health provider. The dentist visit was for treatment of an oral health ailment instead of for prevention of conditions associated with premature births. Therefore, private health plans, including the GIP, are paying for a service that is used by only one out three pregnant women. There are personal and system reasons that explain this behavior. In addition, during 2009 CSOMI reported that 56 pregnant women received dental services, where most of these services were for oral evaluation (n=25), dental cleanse (n=31) and treated cavities (n=22).

Maternal obesity during pregnancy is associated with many complications such as cesarean delivery, macrosomia, gestational hypertension, preeclampsia, gestational diabetes mellitus, fetal death, and possible birth defects. Maternal obesity also increases the long-term risks for the fetus. Children born to obese mothers are twice as likely to be obese and to develop type 2 diabetes later in life. Obesity during pregnancy is also associated with greater use of health care services and longer hospital stay. The ESMIPR 2008 collected data to estimate the BMI at the beginning of the pregnancy (height and weight). Among 1,738 surveyed mothers who reported their pre-pregnancy height and weight, it was found that 51.4% had a normal BMI (18.5 kg/m^2 to 24.9 kg/m^2), 24.1% were overweight (25 kg/m^2 to 29.9 kg/m^2), 16.7% were obese ($\geq 30 \text{ kg/m}^2$), and 7.7% were underweight ($<18.5 \text{ kg/m}^2$). Almost one half of surveyed women began pregnancy with an inappropriate BMI. The BMI is used to guide prenatal care providers in the estimation of the number of pounds that the pregnant women should gain during the course of her pregnancy. However, 23.3% of the group of studied women gained weight below the recommendations and 41.5% gained more than the recommendations. Findings herein described may reflect poor nutritional behaviors among pregnant women in the Island.

Aside from giving services to infants and children, the WIC Program also attends women during pregnancy and postpartum period. During fiscal year 2008-2009, the WIC program served 62,874 pregnant women. The most frequent risk factors for enrollment in the WIC program were: overweight/obesity 39.6%, decreased weight gain during pregnancy 22.1%, increased weight gain during pregnancy 19.8%, anemia 18.9% and underweight 14.2%.

Gestational diabetes mellitus is a carbohydrate intolerance leading to hyperglycemia with onset during pregnancy. Data from BRFSS 2008 reports that 11.6% of the women were told by a doctor that had diabetes and 0.7% had pregnancy related diabetes. However, according to 2006 birth certificates, approximately 2% of the women were diagnosed with gestational diabetes and 0.7% had diabetes before pregnancy.

Other conditions reported in data from the birth certificates (2006) were hypertension before pregnancy (1.4%), preeclampsia (4%) and eclampsia (0.2%). All of these conditions are risk factors that could complicate pregnancy and/or labor.

According to ESMIPR 2008, the prevalence of pregnancy complications requiring between one and over four hospitalizations was 26.5%. Among the most common reasons for hospitalizations were premature contractions (44.1%); vomiting and dehydration (20.1%); placenta problems and bleeding (14.0%); urinary tract infections (12.7%); high blood pressure (9.2%); diabetes (7.8%); and others (23.1%). Almost all these conditions are associated with a high proportion of prematurity and LBW babies.

According to data provided by ASES, during 2009 around 0.04% of women that were pregnant and were insured by GIP had perinatal depression. On the other hand according to data from the Health Insurance Commissioner 0.01% the claims of women of 10 to 14 years old were due to perinatal depression.

Lifestyle

Smoking, alcohol consumption, drug abuse, domestic violence during pregnancy and sexual intercourse with infected partners are behaviors and lifestyle factors that contribute to the escalating rates of low birth weight (LBW), and infant morbidity and mortality in Puerto Rico. As many studies have demonstrated worldwide, women who practice unhealthy behaviors are more likely to have LBW infants. These seem to be important factors that are currently impacting an unknown but significant number of expectant women in our Island.

The ESMIPR 2008 found that 2.7% of surveyed mothers smoked, 3.8% reported alcohol consumption and 0.5% used some illicit drug during the pregnancy. Smoking during pregnancy was significantly higher in unmarried women. In contrast, the proportion of women who smoked was significantly lower as the number of years of education completed increased. Similarly, women who were employed were less likely to be smokers. Women holding the GIP also showed a significantly higher level of smoking compared to those who had private health insurance. Late entry or no prenatal care at all and a baby with a low birth weight were associated with increased smoking.

Having sexual intercourse with infected partners constitutes a behavioral and lifestyle factor that contributes to a broad array of poor birth outcomes: stillbirths, LBW, prematurity and neonatal mortality among others. In PR a significant proportion of WRA are infected with sexually transmitted infections (STIs) and many of them go undetected during the prenatal period.

Early, continuous, comprehensive and quality prenatal care is the most cost-effective strategy to detect, treat and prevent STIs. However, several birth outcomes suggest that there are perinatal system failures that contribute to these preventable adverse newborn outcomes.

According to Vital Statistics data (2006), 4.2/1,000 live births of the women were diagnosed and/or treated of HIV/AIDS during pregnancy. Other STI's reported in the birth

certificate were Gonorrhea (0.6/1,000), Syphilis (1.1/1,000), Chlamydia (16.6/1,000), Hepatitis B (0.7/1,000), Hepatitis C (0.9/1,000) and Genital Herpes (0.3/1,000).

Congenital syphilis may be considered an outcome of an unhealthy behavior of pregnant women, as well as an indicator of poor quality prenatal care. It is important to highlight that a total of 146 cases of congenital syphilis were identified during the period of 2000 to 2009 (Figure II-7). During this period 62.8% of the mothers with congenital syphilis case, reported receiving prenatal care, however only 10.7% reported this prenatal care as adequate (12 visits or more). Of the 146 cases of congenital syphilis, 11% of the mothers were treated before pregnancy, 31% during the pregnancy and 58% never received a treatment. The treatment was adequate for 94% of those that received it before pregnancy; however, 33% of the women that received treatment during pregnancy had an adequate one.

In summary, women with cases of congenital syphilis are between 20 to 39 years old, had inadequate or no prenatal care, had inadequate syphilis treatment, are single, are insured by the Government Health Plan and are residents of the Health Regions of Bayamón, Metro and Ponce. Persistence of Syphilis cases is an indicator of a public health problem. Based on the prevalence of congenital syphilis we must ensure that the standards for prenatal care related to screening of gonorrhea and Chlamydia are being implemented.

There is a need of a well coordinated and concerted action plan between the evolving health care system in Puerto Rico, other public agencies and community intervention programs concerned with providing services to victims of domestic violence during or around the time of pregnancy. Several research studies suggest that women may be at higher risk of domestic violence by intimate partners around the time of pregnancy. Therefore, pregnancy provides a window of opportunities for the identification and management of abuse against women. This is so because women usually come in contact more frequently with the health care system during pregnancy. However, primary health care providers (MD's, RN's, social workers, nutritionists, and others) need to be very well trained to appropriately perform screening for domestic violence at all their interventions. In 2008, the ESMIPR revealed a history of physical abuse sometime during the twelve month before pregnancy by their husband or partner in 1.6% of surveyed recent mothers. Also data from CAVV for the fiscal year 2008-2009, reports that services were offered to two women that were pregnant during an episode of domestic violence.

The adverse effects of domestic violence during pregnancy have been documented in the scientific literature. However, most medical providers do not perform the practice of universal screening for domestic violence during prenatal care visits as part of the routine health care of the pregnant women. Although the public health sector is keenly aware of the importance of the universal screening and the economic benefits of preventing domestic violence, one of the most difficult barriers to implementing universal screening for domestic violence is motivating the medical providers to adopt this intervention in their practices. Medical providers are often oblivious to the importance of public health issues

such as universal screening for substance use and domestic violence and the consequences that an inadequate identification of these risks poses for them and their practice.

It becomes clear that to decrease infant mortality and morbidity on the Island we must intervene to eliminate or at least ameliorate the lifestyles and high-risk behaviors in which our pregnant women engage. Therefore, developing, establishing and implementing the practice of universal screening for alcohol consumption, smoking and illegal drug use in pregnant women, as well as for domestic violence is a worthwhile endeavor in trying to decrease IM and women's homicides. This intervention should be included as part of the standards of care for prenatal care.

Fetal Deaths

Trend analysis shows (Figure II-8) that although fetal death rates increases some years to later decrease, the rate has kept stable, since there's no significant change between years during the study period. However, the target set by Healthy People 2010 regarding fetal deaths is 6.8/1,000 live births and by 2006, 493 stillbirths were registered in Puerto Rico. This represents a stillbirth rate of 10/1,000, which is 1.5 times higher than the established goal.

A descriptive analysis of fetal death revealed that 59.2% of the mothers began prenatal care during the first trimester of pregnancy, 57.6% of stillbirths had a gestational age between 20-27 weeks whereas only 10.5% were ≥ 37 weeks old and 84% were low birthweight and very low birth weight. The five leading causes of death of stillborns in order of frequency were fetus and newborn affected by maternal factors and by complications of pregnancy (35.7%), fetal death of unspecified cause (27.6%), prematurity and low birthweight (24.3%), congenital anomalies (4.5%), and certain conditions originated during the prenatal period. This situation reflects problems associated with maternal health prior to pregnancy as well as problems related with the quality of care received during pregnancy.

As evident with Vital Statistics data as well as the literature some causes of stillbirth are known, such as diabetes or high blood pressure affecting the mother. However the cause of more than half of all stillbirths is unknown. Improved understanding of stillbirth may lead to ways to prevent it.

Cesarean Section

Historically, c-section rates in Puerto Rico have been higher than those in the mainland USA (Vázquez-Calzada, 1988). In Figure II-9 it is evident that over the last 17 years the c-section rates increased. Since 1990 to 1995, C-section appeared to be decreasing, although it was only significant ($p < 0.05$) from 1994 to 1995. However, c-section increased in a significant rate ($p < 0.05$) since 1996 until 2006.

The exponential increase of the c-section rates began at 1995, just when the Health Care Reform was established in almost the entire Island. This gave more access to women of low income to c-section, which had a higher cost for them before the Health Care Reform

and therefore could be one of the reasons for the increase. However, even though the costs of vaginal births were even with c-section in the early 2000's, this didn't have any effect over the increasing c-section rates.

According to the literature, maternal age is one risk factor for c-section. However a closer look to vital statistics data from 1990 to 2006 shows that c-section rates increased for all age groups, even though c-section rates were higher for women 35 years or more. Labor induction before 38 weeks of gestation is not recommended. However in 2006, about 12% of the premature births were induced and 36% of these induced premature births were delivered by a c-section after induction.

The MCH Division completed several studies aimed at understanding the increasing c-section rates. A descriptive study was carried out to provide updated information to concerned individuals and organizations to generate discussion regarding the possible causes that lead to the increased use of this birthing method in Puerto Rico. Stratified analyses from linked birth and death files provided by the State Vital Statistics Office were performed using the most relevant data available to describe the picture and to generate hypotheses regarding the problem. A total of 183,400 c-section live births for the 1990-98 period were evaluated. The c-section delivery rate had increased from 31.0% in 1990 to 35.1% in 1998. Primary C-section rates rose from 19.9% to 21.2% (6.5% change) and repeated c-sections increased from 13.5% to 13.9% (3%). Overall, c-section rates vary greatly according to maternal age and were higher for mothers with private health insurance. Tuesdays (18.3%) followed by Wednesdays (17.8%) were the most frequent days and Sundays (6.7%) followed by Saturdays (8.4%) were the least frequent for c-sections and the majority of the procedures were performed in the afternoon (56.9%). The procedure was performed more frequently between 12:00 and 6:00 PM. These findings suggest that convenience may be an underlying factor for the increase in C-section rates in Puerto Rico.

A c-section Evaluation Committee was created and analyzed the findings of the study conducted by the MCH staff. They generated a list of medical and non-medical reasons that may lead to a c-section. In order to prove or reject these reasons, two other studies have been conducted.

The first one was a chart audit of a representative sample of 560 cases of c-section in 1999 conducted in 2002. This study did not prove that the high rate of c-section could be explained by existence of medical conditions; at least, the evidence was not found in the evaluation of the vital files nor hospital records.

The other study recommended by the C-section Committee was a survey of women subjected to c-section. From July 2004 to February 2005 the MCH staff (Marianne Cruz-Carrión, MS, Evelyn Torres-Rodríguez, MS, Roberto Varela-Flores, MD, MPH, Himirce Vázquez-Rivera, MD) conducted the study entitled "Election of Childbirth By Cesarean

Delivery: Attitudes and Experiences of the Woman and Physician Characteristics in the Decision Making”. The study looked for associations between attitudes and experiences of the woman and the characteristics of the physician in the decision making to deliver by c-section. The methodology consisted of a self-administered questionnaire that collected socio-demographic data, medical history, prenatal care utilization, experiences before and during pregnancy, delivery information, newborn data, and the mother’s opinion about and preference for the type of delivery. It was submitted to 1,004 primiparous women (502 cases and 502 controls) who had a live birth in 31 hospitals that registered 10 births or more per week during 2002. Adjusting by socio-demographic data, medical history, prenatal care utilization, experiences before and during pregnancy, delivery information, and newborn data, the risk of having a cesarean delivery increases when the birth is attended by a male obstetrician (OR=2.02; p=0.04). In conclusion, the woman’s attitudes and experiences and the sex of the physician may affect the decision of the method used for delivery. Efforts to reduce the incidence of cesarean section need to focus on the continuing education of health care providers and on reducing unintended pregnancies, negative experiences and concerns during pregnancy.

To compare trends in cesarean delivery during 1992-2002 among Puerto Rican women who delivered in Puerto Rico and on the US mainland, CDC and the Puerto Rico Department of Health analyzed birth certificate data from the National Vital Statistics System (NVSS). As a result, during 1992-2002, total and primary cesarean rates were consistently higher in Puerto Rico than among Puerto Rican women on the mainland. From 1996 to 2002, total and primary cesarean rates increased for Puerto Rican women in both places of delivery, but rates increased more sharply for women in Puerto Rico than on the mainland. The results suggest focus on lowering the rate of primary cesarean deliveries, especially among women at low risk for a cesarean delivery.

Another study (Farr et al., 2007) explored the differences in the rates of primary cesarean delivery among Puerto Rican Women that delivered on the Island and on US mainland during 2002. Distribution of certain risk factors for cesarean delivery of births in Puerto Rico in 2002 was compared with births in Puerto Rico during 1996 and births on the mainland during 2002. Results showed, risk for cesarean delivery was higher in Puerto Rico in 2002 than in 1996 (RR=2.1; 95% IC= 2.0-2.3) and on the mainland in 2002 (RR=2.1, 95% IC= 2.2-2.6). This translates into one additional cesarean delivery in Puerto Rico in 2002 for every 4.2 live births, controlled for examined risk factors. Higher rates of cesarean delivery in Puerto Rico in 2002 could not be explained by risk factors. Until further research reveals ways to safely reduce the rate of cesarean delivery in Puerto Rico, physician, public health practitioners, and other stakeholders may need to focus their efforts on reducing rates among low risk women and those with no labor complications.

Breastfeeding

According to the American Academy of Pediatrics (AAP) Policy Statement on Breastfeeding, women who don’t have health problems should exclusively breastfeed their infants for at least the first six months of life. The AAP suggests that women try to

breastfeed for the first 12 months of life because of the benefits to both the mother and baby.

Breastfeeding benefits the mother. In response to the baby's sucking, the mother's body releases a hormone that makes her uterus contract and get smaller. Many mothers also get emotional benefits from breastfeeding because of the closeness of this interaction with the baby and from the satisfaction of helping to nourish their babies. In addition, some research suggest that mothers who breastfeed their babies have fewer episodes of post-delivery depression. Also, there is evolving evidence to indicate that certain types of cancer (such as breast, uterus, and ovarian cancer) occur less often in mothers who have breastfed their babies.

According to ESMIPR 2008 (Figure II-10), breastfeeding immediately post-partum (67.7%) has increased almost 25% ($p<0.05$) since 2002 (54.3%). After 6 months from delivery these mothers were queried about breastfeeding, and by 2008 about 26% ($p<0.05$) reported still breastfeeding, an increase of 29% since 2002 (20%). Although breastfeeding for 12 months is not as frequent as post-partum or after 6 months, there is evidence that this is also significantly increasing by 40% (8% in 2002 vs. 11.2 %in 2008).

Several laws were enacted in Puerto Rico aimed at protecting the breastfeeding mother. Law No. 32 enacted on January 10, 1999, establishes areas designed for breastfeeding and change diapers for young children in malls, government centers, ports and airports. Law No. 239 of November of 2006 amends Law No. 427 of 2000, increasing to one hour the time working moms have for breastfeeding or milk extraction at their work setting. In addition, on March 13, 2004, Puerto Rico enacted Law No. 79 aimed at prohibiting the administration of any milk substitute to newborns without mother's consent. Law No. 95 enacted April 23, 2004, prohibits discrimination against women who breastfeed in any public setting.

Integrated Index of Maternal and Infant Health Status

In order to assess the maternal and infant health status and to compare it by municipalities, an Integrated Index of Maternal and Infant Health Status (IIMIHS) by Municipality was developed by the MCH Division in 1998. The Index includes 15 indicators selected from birth and death files. The IIMIHS is comprised of five sociodemographic indicators: (1) Birth rate, (2) Percent of unmarried women, (3) Percent of adolescent mothers, (4) Percent of unmarried adolescent mothers, and (5) Percent of mothers with less than 12 years of education. Two are related with the adequacy of prenatal care: (1) First trimester admission rate, and (2) Kotelchuck Index. The remaining eight reflect the pregnancy outcome indicators: (1) Percent of prematurity, (2) Percent of VLBW, (3) Percent of LBW, (4) Neonatal mortality, (5) Postneonatal mortality, (6) Infant mortality rate, (7) Stillbirth rate, and (8) Perinatal mortality rate (Table II-3).

Making use of available data from birth and death files, the value of each of the 15 indicators is determined for the 78 municipalities. These are ranked according to the value

of the indicator. The sum of all the 15 ranks obtained by a municipality constitutes the IIMIHS. In theory, if a municipality ranks in the first position for each selected indicator it would have an IIMIHS of fifteen (15). In the contrary, if it ranks in the last position (78) for each indicator it would have an index of 1,170. The IIMIHS has been used as a tool for the allocation of resources and to raise awareness among different stakeholders regarding maternal and infant health across different geographical areas (Table II-3).

In 2006, there were 48,744 live births in Puerto Rico and the crude birth rate was 12.4 per 1,000 inhabitants. Only 70 births (0.1%) occurred outside a health facility. Nearly one of every two births (49.3%) was performed by cesarean section.

Of all registered births, 58% were to unmarried women, and 18.3% to women under 20 years of age. About 8 in 10 (83.2%) adolescent mothers were unwed. Over one in five (21.2%) of all mothers had not attained a high school diploma.

More than eighty percent (80.4%) of all births occurred in women who initiated prenatal care during the first trimester. On the other hand, 75.8% had an adequate Kotelchuck Index.

The interrelation of sociodemographic factors and quality prenatal care contribute to maternal, fetal and infant outcomes. An analysis of 2006 births shows the following outcomes: 1.5% of all births were VLBW; 13% LBW; 19.9% were born prematurely. The neonatal mortality rate was 6.9/1,000 live births; 2.2/1,000 died during the postneonatal period and the infant mortality rate was 9.1/1,000 live births. The perinatal mortality rate was 9.1 and the stillbirth rate reached 10 per 1,000 births.

The 10 best municipalities according to the Integrated Index of Maternal and Infant Health Status in 2006 were Añasco (211), San Sebastián (214), Las Marías (215), Culebra (221), Hatillo (242), Isabela (246), Moca (261), Guaynabo (284), Aguada (287) and Hormigueros (296) (Figure II-11).

By contrast, the worst 10 municipalities were Vieques (670), Loíza (643), Cataño (603), Peñuelas (601), Villalba (594), Guayama (574), Canóvanas (568), Santa Isabel (564), Barranquitas (555) and Orocovis (551). Figure II-11 depicts the localization of these municipalities.

Maternal Mortality

Infant and maternal death rates are two sentinel indicators that reflect not only the maternal and infant health status, but also the socioeconomic well-being of a community or a nation. Maternal mortality (MM) is an important public health problem that affects the woman, the

family and society overall. Reports of maternal deaths based on death certificates are usually underestimated. Actual numbers are two to three times greater.

Several studies had identified under-reporting of maternal deaths in Puerto Rico due to misclassification of the cause of death. In 1982, Comas and others found 71.4% under-reporting of maternal deaths. These and other studies led to the inclusion of checkbox No. 21 in the death certificate in 1989. This checkbox helps to identify women who have been pregnant at the time of death or during the 12 months prior to death.

According to vital statistic reports from 1991 to 2006 (Figure II-12), the rate of maternal deaths fluctuated from 20.2 to 5.9 per 100,000 live births. However, it is important to highlight that these deaths are those that occurred around the pregnancy, childbirth and the puerperium period and represent the most severe pregnancy complications leading to maternal deaths (ICD 10 Codes O 00-99). Trend analysis suggests high data variability thru time. Maternal deaths are rare and since the denominator is large, a slight change in the number of cases provokes huge changes in maternal rate. Logistic Regression Models suggest that the trend from 1990 to 2006 is decreasing; however because of the variability based on the R Square Model, or the total amount of variance explained by the model is small ($R^2=0.23$), and because the p value is greater than 0.05 we can therefore conclude that the tendency shown could be random.

Maternal and infant mortality are basic health indicators that reflect the nation's health status and well being. Current MMR's are unacceptable, not only in Puerto Rico, but also in the US mainland, considering the amount of resources and technology invested in health care services. Since 1982, no progress has been made in the U.S. towards achieving the Healthy People 2010 goal of 3.3 maternal deaths per 100,000 live births. In fact, data for 2006 showed MMRs of 5.9 per 100,000 live births in PR compared to 13.3 per 100,000 live births (2006) in the U.S.

Since 2005, the PR MCH Program developed a Maternal Mortality Surveillance System (SiVEMMa, Spanish acronym). The main objective of SiVEMMa is to estimate the frequency and main causes of maternal deaths. This system is based on the revision of death certificates, as well as birth and fetal death certificates. Also SiVEMMa uses autopsy reports and medical records as other sources of information. A Committee of Maternal Mortality Surveillance was also established almost at the same time than SiVEMMa. This committee, composed of professionals from different health areas, evaluates the cases identified and recommends strategies aimed at preventing deaths related to pregnancy.

The most recent SiVEMMa study evaluated cases from 2002 to 2004. During this period 154,931 births occurred and 80 cases were identified. Among these, 53.8% were pregnancy related, 20% not-pregnancy related and 26.3% undetermined. Of the 53.8% cases pregnancy related, 27% were caused by preeclampsia or eclampsia, 23% embolism and 12% by cardiomyopathy. Women of 34 years or more are three times more at risk of a maternal death compared to women less than 34 years old. The Maternal Mortality

Surveillance Committee examined maternal death profiles and identified those women with chronic conditions that did not receive the adequate medical care. The Committee also concluded that many women did not perceive or did not acknowledge the signs and symptoms of a risk that could cause death, like for example hypertensive conditions induced by pregnancy. The Committee recommends that health providers should emphasize on educating women in terms of how to look at their health in a better way.

c. Infants

Sociodemography

During 1990 to 2006, an average of 59,182 babies were born alive in Puerto Rico. Sadly, every year about 651 of the babies died before the celebration of their first birthday. Most of these babies (73.6%) died during the neonatal period. These shocking statistics should make all stakeholders concerned, take notice and action regarding newborn health.

Infant Health

A healthy infancy is composed by several factors, including screening, feeding, routine medical checkups, and oral health, among others. Many of these factors are taken under consideration by most of the parents, however because of lack of knowledge some of them do not take them under consideration.

Right after birth the infant is screened for serious developmental, genetic, and metabolic disorders so that important action can be taken during the critical time before symptoms develop. Most of these illnesses are very rare. A total of 45,112 live newborns were screened at birth for hereditary diseases during fiscal year 2008-2009, where 11 were positive for congenital hypothyroidism, 3 for phenylketonuria (PKU), 9 for Sickle Cell, 1 for galactosemia and 2 for congenital adrenal hyperplasia.

As mentioned before, the AAP suggests breastfeeding for the first 12 months of life. Breast milk provides the right balance of nutrients to help an infant grow into a strong and healthy toddler. Breastfed infants, and those who are fed expressed breast milk, have fewer deaths during the first year and experience fewer illnesses than babies fed formula. Some of the nutrients in breast milk also help protect an infant against some common childhood illnesses and infections, such as diarrhea, middle ear infections, and certain lung infections. Some recent research also suggests that breast milk contains important fatty acids (building blocks) that help an infant's brain develop. Two specific fatty acids, known as DHA and AA, may help increase infants' cognitive skills. Many types of infant formulas available in the United States are fortified with DHA and AA, and all formula available for preterm infants is fortified with these fatty acids. According to ESMIPR 2008 (Figure II-10), breastfeeding immediately post-partum (67.7%) after 6 months from delivery (25.8%) and 12 months after delivery (11.2%) increased significantly ($p < 0.05$) since 2002.

Newborns are also screened for hearing loss before leaving the hospital, according to Law #311 and Regulation #114 enacted on 2003 and 2004, respectively. This percent increased significantly (2.9%) from 25.3% in 2004 to 97.9% in 2008.

A newborn usually needs to be seen by a health care provider every few months. Babies will get their recommended immunizations during these visits. Routine exams and screenings help prevent and treat health problems as well as chart their growth and development. As children reach their first birthday, most do not need to go as often. However, most of the time, visits to a health care provider are for other reasons that are not routine.

According to the principal health insurance companies of Puerto Rico (private and governmental), infants (0 to 12 months) mainly visit a physician's office because of routine immunization (26.5%). However, acute upper respiratory infections of multiple or unspecified sites (18.8%), acute bronchitis and bronchiolitis (11.0%), health supervision of infant or child (8.2%), acute nasopharyngitis or common cold (4.2%) and viral/chlamydial infection in conditions classified elsewhere and of unspecified site (3.8%) were the main reasons for a physician's visit. Aside from routine immunization (44.6%) and health supervision of infant or child (12.8%), ambulatory services such as acute upper respiratory infections of multiple or unspecified sites (12.6%), acute bronchitis and bronchiolitis (5.3%), contact dermatitis and other eczema (3.2%), viral and chlamydial infection in conditions classified elsewhere and of unspecified site (2.9%) and general symptoms (2.1%) were the most prevalent among infants. Most of the frequent use of emergency services among infants were because of acute upper respiratory infections of multiple or unspecified sites (21.7%), general symptoms (10.9%), acute bronchitis and bronchiolitis (10.3%), viral and chlamydial infection in conditions classified elsewhere and of unspecified sites (9.4%), injury, other and unspecified (7.2%). More than half of the hospitalization claims in infants (51.7%) were due to acute bronchitis and bronchiolitis. Claims of hospitalizations were also due to other non-infective gastro-enteritis and colitis (8.8%), pneumonia, organism unspecified (6.9%), other disorders of urethra and urinary tract (5.3%) and bronchopneumonia, organism unspecified (3.1%). On the other hand, specific delays in development (84%), unspecified mental retardation (7%), special symptoms or syndromes not elsewhere classified (3%), hyperkinetic syndrome of childhood (3%) and neurotic disorders (1%) were the main claims for mental services for infants.

Healthy teeth are important to an infant's overall health. Teeth help them chew food and form words and sounds when speaking. Generally, teeth start appearing between 4 and 7 months of age, but every baby is different. It is recommended to start cleaning the baby's teeth twice a day as soon as the first tooth appears. Until the child is 1 year old, a wet washcloth or gauze can be used to clean the teeth and gums. When the child is 12 to 18 months old a soft baby toothbrush and a small dab of toothpaste that does not have fluoride can be used. A dentist should evaluate an infant around the first year and every six months thereafter. During 2009, CSOMI received 83 participants between 0 to 1 years of age, where 47 received an evaluation, 77 had a cleansing and fluoride was applied to 50 infants.

Perinatal Mortality

The perinatal period is defined as 28 weeks of gestation or more to 7 days or less after birth. Perinatal deaths in 2006 was 9.4/1,000 LBs, which is 1.3 times higher than the Puerto Rico Healthy People objectives for 2010 (7.4/1,000 LBs). The perinatal mortality is a reflection of the health of the pregnant woman and newborn and reflects the pregnancy environment and early newborn care. According to Vital Statistics (2006) the principal causes of perinatal death were prematurity and low birthweight (45.1%), Fetus and Newborn affected by complications during pregnancy, labor and delivery (16.3%), fetal death of unspecified cause (14.8%), congenital anomalies (9.8%) and other respiratory disorders originated during the perinatal period (9.8%).

Infant Mortality

In 1913, Julia Lathrop said “infant mortality is the most sensitive index we possess of social welfare” (U.S. Children’s Bureau, 1913). Negative social conditions, unhealthy physical environments, quality of prenatal, perinatal and postneonatal care have a bigger impact on a newborn than in any other period of life. Therefore, the number of infants who die before the first birthday is a sentinel indicator not only of health conditions but also of the socioeconomic conditions of a community or nation.

The target for the Infant Mortality Rate (IMR) set by the Puerto Rico Healthy People 2010 is 6.2 deaths per thousand live births (1,000 LBs). In 2006, a total of 442 deaths occurred in children under 1 year, 29 deaths less than in 2005. The IMR in 2006 was 9.1/1,000 LBs, the neonatal mortality rate was 6.9/1,000 LBs and the postneonatal mortality rate was 2.2/1,000 LBs. Trend analysis (Figure II-13) shows that infant mortality has decreased significantly 2.7% since 1990 (X^2 for trend $p < 0.05$). Neonatal and postneonatal mortality has also decreased significantly (X^2 for trend $p < 0.05$) almost at the same rate (2.7% and 2.8%, respectively) for the same period. The current infant mortality rate in the Island is 1.2 times higher than Puerto Ricans from the U.S. mainland (7.7/1,000) and 1.5 times above the set target for 2010.

Looking at the IMRs by health regions, Fajardo (7.2/LBs), Bayamón (7.3/1,000 LBs) and Arecibo (7.7/1,000 LBs) were the health regions with the lowest IMRs. In contrast, Mayagüez (12.1 per 1,000 LBs) and Ponce (9.9/1,000 LBs) were the health regions with the highest IMRs. During 2006, infant mortality did not occur in five (5) municipalities (6%), whereas 26% of the municipalities (20) had an IMR below the Puerto Rico Healthy People 2010, ranging from 1.8/1,000 LBs in Manatí to 6.1/1,000 LBs in Florida. On the other hand, 50% of the municipalities (39) recorded IMRs above 9.1/1,000 LBs observed in the entire Island. Figure II-14 portrays the health regions and municipalities with the IMRs below 6.2/1,000 as suggested by Healthy People 2010. Although in the southeast there is a cluster of five (5) municipalities, most of these municipalities are localized to the north of the Island.

The main causes of infant mortality during 2006 were prematurity and low birthweight (43.4%), congenital anomalies (15.2%), other respiratory disorders originated during the perinatal period (5.2%), other perinatal conditions (4.8%), septicemia (3.6%), sepsis (3.4%)

and other causes (24.4%). Therefore, prematurity and low birthweight and congenital anomalies are the causes of almost 60% of infant deaths.

Babies born weighing less than 5 pounds, 8 ounces (2,500 grams) are considered low birthweight (LBW). LBW babies are at increased risk for serious health problems as newborns, lasting disabilities and even death. The likelihood of an infant being a LBW increases with an earlier birth. Very low birthweight (VLBW) babies (those who weigh less than 3 pounds, 5 ounces or 1,500 grams) have the highest risk for health problems.

In 2006, 13% of babies were LBW and 1.4% VLBW (Figure II-15 and II-16). According to the Puerto Rico Healthy People 2010 objectives, LBW babies should be reduced 25% from baseline (10.9%) and VLBW should decrease to 1%. However, these rates increased significantly since 1990 (2.1% and 1.7%, respectively). Furthermore, about 59% of LBW babies in 2006 were premature, which is one of the main reasons for an infant to be born LBW.

Premature babies are born before 37 completed weeks of pregnancy. The causes of premature delivery are not thoroughly understood. In some cases, a pregnant woman may have a health problem or pregnancy complications that increase her risk of delivering prematurely. Women who have had a previous preterm delivery, a multiple pregnancy, or have certain abnormalities of the uterus or cervix also are at increased risk. More often, preterm labor develops unexpectedly in a pregnancy that had been problem-free.

In addition to a greater risk of death during the first year of life, premature infants are also at higher than normal risk for lifelong complications such as cerebral palsy, chronic lung disease, gastrointestinal problems, mental retardation, vision loss and hearing loss. As adults, premature infants may face a higher than normal risk for heart disease and diabetes.

About 20% of babies were born premature during 2006 (Figure II-17); this represents a significant increase ($p<0.05$) of 3.7% since 1990. Premature births in Puerto Rico are 1.5 times greater than the U.S. (13%) and 2.7 times greater than Healthy People 2010 objective (7.1%). More than 75% (78% in 2006) of the premature births occur during 34 to 36 weeks of gestation (Figure II-18). In spite of the medical advances aimed at increasing the survival of these babies, nearly 72% of the infants that died in 2006 before the first year of birth were premature. Another interesting fact is that 36% of premature births were delivered by a c-section after being induced.

Premature births increased significantly in 1997; since then prematurity increased significantly ($p<0.05$) at a wider rate. This could be related to certain events occurring in Puerto Rico during the 1990's. As mentioned before, the Health Reform was established in 1993; this triggered rates such as birth rates in adolescents and cesarean deliveries. It is believed that many of the premature births are consequences of many elective C-sections.

Of the 9,678 premature births that occurred in 2006, 60% were from mothers with no risk factors (5,827), infections or complications during pregnancy. An interesting fact is that about 37% of these births were delivered by a C-section and most of them (78%) were during 34 to 36 weeks of gestation. Even more, 12.1% of premature births of less than 34 weeks of gestation died before the first birth day, whereas 0.77% births of 34 to 36 weeks of gestation died before the first birthday. Therefore it is believed that one justification for elective c-section during the late preterm period is that survival of preterm babies' increases with the gestation period. However, there is evidence that late preterm babies are significantly less developed than a full term baby (March of Dimes) and therefore at more risk for mortality and long term complications.

Fetal growth restriction or small for gestational age (SGA) is another reason for an infant to be born LBW. SGA means that a fetus or infant is smaller in size than normal for the baby's gender and gestational age. SGA may be a full term baby, but is underweight. In 2006, 41% of LBW babies were 37 weeks or more of gestation. It is difficult to completely separate factors associated with prematurity from those associated with SGA.

The second cause of infant mortality is congenital malformations (15.2%). Birth defects are defined as abnormalities of structure, function, or body metabolism that are present at birth. These abnormalities lead to mental or physical disabilities or are fatal. There are more than 4,000 different known birth defects, ranging from minor to serious, and although many can be treated or cured, they're one of the leading causes of death in the first year of life. Birth defects can be caused by genetic, environmental, or unknown factors. A closer look at the data shows that most of the premature babies have an underlying birth defect, which might also be the cause of prematurity and death. Furthermore, the vital statistics mortality data for 2006 analyzed by birth weight showed that birth defects are the leading cause of infant mortality in the "2,500-1,500 grams" (25%) and "2,500 or more" (38.3%) groups. Still, prematurity continues to be the leading cause of infant mortality in the "less than 1,500 grams" group.

As mentioned earlier, most of the infants' deaths occur during the neonatal period (Figure II-19), which is during the first 27 days after birth. For 2006, this rate is 1.5 higher than in the U.S. mainland (4.5/1,000 LBs) and 1.3 above the Puerto Rico Healthy People 2010 objective of 5.4/1,000 LBs. As in infant mortality, the leading cause of neonatal death for 2006 was prematurity and low birthweight (57%), followed by congenital malformations (15.6%) and other respiratory conditions originated during the perinatal period (6.6%).

While neonatal deaths are associated with events surrounding the pregnancy and delivery, the postneonatal deaths are more likely associated with conditions or events that arise after delivery and discharge of the baby from the hospital. The postneonatal mortality rate (Figure II-19) should not surpass the rate of 2.4/1,000 LBs by 2010 (Healthy People Objectives). In Puerto Rico, the postneonatal mortality rate reached this objective during 2006 (2.2/1,000 LBs). The cause of deaths in the postneonatal period reflects the effect of the use of technology in preventing deaths of VLBW babies and those with congenital

anomalies. According to Vital Statistics from 2006, sepsis (15%), congenital malformations (14%) and disease from the circulatory system (11.1%) were the leading causes of death during postneonatal period.

Aware of how important it is to understand infant mortality in Puerto Rico; the PR MCH Program established the Fetal and Infant Mortality Review (FIMR). The FIMR is a community action process that continually assesses and improves service systems and resources for women, infants, and families through confidential and anonymous review of individual cases. FIMR complements local population-based fetal and infant mortality data. It identifies critical community strengths and weaknesses as well as unique health/social issues associated with poor outcomes. FIMR was established in Puerto Rico during 2006 with trainings and workshops; case reviews began during 2009, only on the municipality of Mayagüez, although cases of Ponce are expected to be reviewed later on. Until now, recommendations in areas such as nutrition, prenatal care, preconceptive care, support system, education and hospital services were already suggested. It is expected to disseminate these recommendations to the relevant agencies and stakeholders with the objective of decreasing the infant mortality rate in Puerto Rico.

B. Children and Adolescents Health:

Size and Composition

According to the Puerto Rico Community Survey 2007, in Puerto Rico there were 1,120,738 children and adolescents aged 0-19 years. This figure represents 28% of the overall population in Puerto Rico. However, as shown in Table II-4, the size of all child and adolescent groups declined 12.0% from 1980-2007. This decline may be explained by the drop of the natality rate observed during the last decade as well as the migration of Puerto Rican WRA to the U.S. mainland. As a matter of fact, in 2006 the number of births reached a never-seen low number of only 48,744. Of these, only 42,083 (86.3%) were born to Puerto Rican women, 1,302 (2.7%) to Dominicans, 4,568 (9.4%) to women from US mainland and 769 (1.6%) to women of other nationalities.

Improving the health of children and adolescents is one of the Commonwealth of PR's highest priorities. Health insurance coverage is critical for improving the overall health and well-being of both mothers and children. In 2006, 65% of all births were to women covered by the GIP. Similarly in 2008-2009, nearly 81.6% of Head Start children had the GIP, 18.2% private health insurance and only 0.39% did not have health insurance. The GIP is financed through a mixture of funds including 79.5% state and municipal funds, 14.6% Medicaid and 5.9% SCHIP funds.

An important determinant of children and adolescent health is having a health insurance. Because Puerto Rico is not usually included in the national surveys intended to assess the health needs of the pediatric population, such as the SLAITS, the Puerto Rico Health Survey was created on 1963. The objective of this survey was to measure some health indicators to obtain a description of the population of Puerto Rico (including the pediatric population) that facilitate planning and administration of health services. The data of 2003

revealed that 5.1% of the population of children and adolescent (0-19 years) in Puerto Rico did not have health insurance. In this population the most prevalent conditions were diseases of the respiratory system (23.9%), diseases of the eye and adnexa (3.6%) and general symptoms and signs (3.2%). The most prevalent causes for hospitalizations were: diseases of the respiratory system (1.1%) and diseases of the digestive system (0.3%) and the most causes for physician's office visits were: diseases of the respiratory system (5.4%), endocrine, nutritional and metabolic diseases (3.7%) and diseases of the digestive system (2.5%).

The impact of childhood poverty on health and well-being is well known. In 2007, nearly 37.2% of families with children in PR were headed by a female householder. This represents an increase over the share of female-headed families with children reported in 2000 (27%). In the US, female headed families increased from 27% in 2000 to 24% in 2007.

Morbidity

Unlike mortality data, morbidity data are more difficult to obtain. Morbidity data can be obtained by means of sample surveys. However, undiagnosed conditions will not be reported. Another problem with surveys is that subgroups with greater access to health care will often appear to have greater incidence of certain conditions.

During the first half of the 20th century, infectious diseases were the primary threat to child health. The first causes of death were pneumonia, gastroenteritis and dehydration, bacterial meningitis, parasitosis, malnutrition, anemia and vaccine-preventable illnesses. However, with the advent of antibiotics, immunizations, purgatives, and other effective medical and environmental interventions such as potable water, pasteurization of milk and electricity, morbidity and mortality from infections declined markedly.

During the first decade of the 21st century, child health problems have become more strongly related to external or environmental and difficult to prevent causes, such as injuries, congenital anomalies, cancer and child neglect and abuse. Therefore, to address current child health problems we must focus on issues such as family structure and support services, injury prevention, reduction of family violence, appropriate management of chronic illnesses, mental health and the provision of social services, among others.

The percentage of children who are adequately immunized is another important indicator of child health. Puerto Rico has one of the highest levels of immunized children. In 2007, the immunization coverage among children between 19 and 35 months of age was 91.2%, compared to 76.1% in the US. In Puerto Rico, vaccine preventable diseases have almost disappeared, except for chickenpox. In 2009, the number of reported cases of chickenpox in children of 1-4 years was 29; 33 cases in the 5-9 years and 124 in the 10-19 age group. In addition only one case of mumps was reported in the 1-4 age group and one in the 5-9 age group.

Intentional Injuries: Child Abuse and Neglect

In spite of Puerto Rico's efforts to prevent child abuse and neglect, the annual number of cases reported to the Department of the Family is overwhelming. Underlying causes for this serious social problem may be related to the significant proportion of unplanned and unwanted pregnancies (65.9% and 5.8% respectively, ESMIPR 2008) and drug abuse in the mother and partner. Frequently the abuser is not the biological father of the affected child. Also, the proportion of children born to teenagers (10-19 years), most of them unmarried (83.2%) is another contributing factor.

On a given day in Puerto Rico, nearly 140 cases of child abuse and neglect are reported to the Department of the Family. However, it is important to highlight that for every reported case, there are three who are being abused. But unfortunately, nobody sees or hears anything, and nobody reports the affected child. In 2008-2009, the numbers of families engaged in this violent behavior was 15,687 and 36,002 children were neglected or abused. Based on the current classification for reporting child abuse and neglect it was found that:

- 18,251 (51.0%) were classified as child abuse and neglect
- 6,799 (18.9%) were multiple abuse
- 4,705 (13.3%) were physical abuse
- 4,247 (11.9%) were emotional abuse
- 2,118 (5.4%) were sexual abuse
- 11 (0.03%) were exploitation

a. Preschool Children Aged 1-4

Morbidity

In 2009-2010, the number of children enrolled in Head Start programs was 34,049. Of these, 16.7% were children with special health care needs. The most common health conditions reported in Head Start children in order of frequency were dental caries 22.0%, bronchial asthma 15.9%, 11.4% had incomplete immunizations at the time of entrance into the Head Start Program, overweight 10.6%, anemia 7.5%, conduct disorders 5.2%. The prevalence of insulin dependent diabetes was 0.1 %.

Among the children enrolled in the WIC Program in 2008-2009, the prevalence of overweight was 39.2%. The other most prevalent conditions among this population were: underweight (18.6%), gastrointestinal disorders (11.1%), and anemia (7.2%).

A group of pediatricians at the PR Pediatric Annual Meeting held in March 2010 said that the most common reasons for ambulatory request of services in preschool children are upper respiratory infections, obesity and gastroenteritis.

According to the principal health insurance companies in Puerto Rico the most common reasons for visits to physician's office were: vaccination (26.5%), acute upper respiratory

infections (17.3%), asthma (6.6%), viral and chlamydial infections (5.4%), acute bronchitis and bronchiolitis (4.3%).

In terms of hospitalizations, the most common reasons were: acute bronchitis and bronchiolitis (19.1%), asthma (16.7%), other non-infective gastroenteritis and colitis (15.0%), pneumonia (13.5%) and bronchopneumonia (7.2%).

The most common reasons for emergency room visits were acute upper respiratory infections (15.9%), injuries (10.5%), general symptoms (9.1%), and gastroenteritis and colitis (8.9%) and viral and chlamydial infections (8.0%).

Regarding mental health, the leading conditions were: specific delays in development (58.7%), hyperkinetic syndrome (17.5%), psychoses with origin specific to the childhood (7.7%), adjustment reaction (5.3%) and disturbance of emotions specific to childhood and adolescence (3.5%).

Vaccination (26.7%), acute upper respiratory infections (13.9%), general symptoms (6.1%), viral and chlamydial infections (5.7%) and other and unspecified anemia (4.3%) were the most frequent conditions for ambulatory care.

Mortality

In general terms, from the period of 1990 to 2006, this age group has shown a decrease in their mortality rates. This decrease was marked by an average annual percent of change of - 3.9%. In 1990 the mortality rate was 38.7 and in 2006 the rate was 15.8 per 100,000.

The leading causes of death in the period of 2000-2006 were: (1) unintentional injuries, (2) congenital anomalies, (3) neoplasms, (4) diseases of the nervous system and (5) diseases of the respiratory system.

b. School Age Children 5-14

As reported by the group of pediatricians that participated in the PR Annual Meeting of the American Academy of Pediatrician Puerto Rico Chapter, the most common conditions seen at the office are: upper respiratory infections, obesity, and hyperactivity syndrome.

According to the principal health insurance companies of Puerto Rico the most common reason to physician's office visits were: acute upper respiratory infections (15.9%), hyperkinetic syndrome of childhood (7.9%), asthma (7.4%), viral and chlamydial infections (7.2%) and allergic rhinitis (4.2%).

In terms of hospitalizations, the most common reasons were: asthma (18.5%), other non-infective gastroenteritis and colitis (12.6%), pneumonia (9.7%), acute appendicitis (8.7%), other cellulitis and abscess (7.6%).

Injuries (15.7%), other non-infective gastroenteritis and colitis (10.6%), acute upper respiratory infections (10.4%), viral and chlamydial infections (9.0%) and other symptoms involving abdomen and pelvis (6.7%) were the top reasons for emergency room visits.

Regarding mental health the principal conditions were: hyperkinetic syndrome of childhood (59.2%), adjustment reaction (10.1%), affective psychoses (5.7%), neurotic disorder (5.5%), and specific delays in development (5.3%).

Also the most common reasons for ambulatory care were: general symptoms (9.2%), upper respiratory infections (8.2%), allergic rhinitis (7.4%), viral and chlamydial infections (6.9%), and other symptoms involving abdomen and pelvis (6.1%).

On the other hand, in 2008-2009 the Department of Education registered 103,118 (nearly 21% overall school aged children) with the following conditions in order of frequency: specific learning disabilities, speech and language impairment, mental retardation, autism, emotional disturbance, multiple disabilities, hearing impairment, visual impairment, orthopedic impairment, and others.

The MCH Division in collaboration with the Alliance for Healthy, Active and Well Nourished Children and Adolescents (AHAWNCA) developed a study in the school year 2008-2009 to estimate the prevalence of obesity and overweight in students of second, fifth, eighth and eleventh grade. At this moment MCH was debugging the database and beginning a preliminary statistic analysis only for second and fifth grade. Previously a sample size was calculated: 988 for second grade and 1,043 for fifth grade. The response rate for each grade was 54.6% and 53.4%, respectively. This sample was stratified by private and public schools, then a sample of schools were selected. To estimate the proportion of students with obesity, overweight, healthy weight and underweight the formula for stratified sampling was used. The standards errors were estimated to obtain the confidence interval.

The preliminary results are for all students in second grade: 23.7% (95% CI: 20.1%; 27.4%) were obese, 14.4% (95% CI: 11.4%; 17.4%) were overweight, 57.1% (95% CI: 52.8%; 61.3%) were healthy and 4.8% (95% CI: 3.0%; 6.6%) were underweight. For the students in private school the preliminary results were: 27.7% obese, 17.6% overweight, 50.9% were healthy and 3.8% underweight. For the students in public school the preliminary results were: 22.2% obese, 13.2% overweight, 59.5% were healthy and 5.2% underweight.

The preliminary results are for all students in fifth grade: 23.5% (95% CI: 19.6%; 27.3%) were obese, 18.6% (95% CI: 15.0%; 22.2%) were overweight, 55.6% (95% CI: 51.1%; 60.1%) were in a healthy weight and 2.3% (95% CI: 1.0%; 3.7%) were underweight. For the students in private school the preliminary results were: 26.0 % obese, 15.1% overweight, 55.7% were in a healthy weight and 3.8% underweight. For the students in public school the preliminary results were: 22.6% obese, 19.9% overweight, 55.6% were in a healthy weight and 2.0% underweight.

In the school year 2006-2007 the Maternal and Child Health Division in collaboration with the School of Dentistry of the University of Puerto Rico developed a study to describe the oral health status of a representative sample of third grade students in Puerto Rico by evaluating the presence of: dental sealants, cavities and missing primary permanent molars. Also the study described the associations of these oral health indicators to socio-demographic and oral health indicators. In this study, 10 licensed dentists evaluated the oral health of third grade students in 57 schools (33 public, 24 private). Also the study identified third grade student's oral health practices by means of an auto-administered questionnaire completed by their parents. The most relevant results of this study were: the prevalence of at least one untreated cavity 40.6%, the prevalence of at least one dental sealant was 17.1% and the prevalence of missing at least one permanent molar was 4.6%. In terms of dental sealant the prevalence of dental sealants among students attending private school was significantly higher than the prevalence of students attending public schools (22.3% vs. 11.3%, $p < 0.05$).

The bivariate analysis revealed that the prevalence of dental sealants among students holding private insurance plan was significantly ($p < 0.05$) higher (19.4%) than students holding the government insurance plan (GIP) (14.2%). In terms of untreated cavities, the prevalence was also significantly ($p < 0.05$) higher among students who their first dental visit was at > 5 years (45.4%), their time since last dental evaluation was more than six months (46.5%), had the practice of going to sleep with a bottle (48.4%), were missing school due to oral health problems (55.6%), attended public school (48.4%), were females (43.0%) and had GIP (50.5%).

In terms of the multivariate analysis the protecting factors for cavities were age at first dental evaluation (< 5 years), prevalence odds ratio (POR = 0.71 (CI 95%: 0.56, 0.91) adjusted by school type, type of health insurance and absence due to oral health problems and the other protecting factor was sealants (POR = 0.37, CI 95%: 0.26, 0.53) adjusted by type of health insurance and school type. The risk factor for cavities were time since last dental visit (> 6 months) (POR = 1.63, CI 95%: 1.27, 2.07) adjusted by school absence due to oral health problems and school type and the other was the practice of going to sleep with a bottle (POR: 1.49, CI 95%: 1.15, 1.94) adjusted by school type, type of health insurance and school absence due to oral health problems. Cavities are most common among children from low income families. Students from public schools and those holding a government sponsored health plan were less likely to have dental sealants. Dental sealant is a preventive measure for the most common disease on children. Efforts should be directed toward eliminating the disparities that exist based on economic status.

Mortality

From 1990 to 2006, the population (5-9 years) has shown a significant decrease in mortality rates with an average annual percent of change of -4.4%. This was a markedly reduction in these rates (Figure II-20).

In the period of 2000-2006, the most frequency causes of death in this age group were: (1) unintentional injuries, (2) neoplasms, (3) diseases of the nervous system, (4) congenital anomalies and (5) diseases of the respiratory system.

c. Adolescents Aged 10-19

In 2007, 15.1% (597,988) of the population in PR was between 10 to 19 years of age; 7.7% were males and 7.4% females. This group has decreased 10.1% since 1990.

Morbidity

The principal health conditions of adolescents are related to unhealthy behaviors and psychosocial factors. Puerto Rican adolescents are involved in a high proportion of unintentional injuries that increase their morbidity and mortality rates. They engage in unprotected sexual behavior leading to unwanted adolescent pregnancy and STIs. The rates of smoking, alcohol consumption and illicit drug use are alarming. These behaviors result in delinquent activity which is the root cause of violence measured by the rates of homicides, suicides and juvenile arrests.

According to the group of pediatricians the most common health conditions among the adolescent group are behavior disorders, irresponsible sexual behavior, and obesity.

Regarding mental health, the Administration of Mental Illness and Anti-Addiction Services (ASSMCA), developed a survey every 2 years called “Monitoring the Future” to evaluate risk behaviors among the adolescent group in public schools of Puerto Rico (middle and high school). The results of the 2005-2007 survey revealed that the most prevalent conditions of mental health in this age group was the use and abuse of alcohol (19.4%), followed by attention deficit disorder (13.1%) and major depression (11.5%). The conduct disorder had the lower prevalence (4.8%). The females had the higher prevalence of major depression (14.8%) compared with males (8.2%). However, males had the higher prevalence of conduct disorder (6.7%) than females (2.9%) and also in the use/abuse of alcohol (21.1% vs. 21.1%) respectively.

Ambulatory Care

Puerto Rican adolescents generally rely on ambulatory care, especially physician offices and the emergency room for medical treatment. In 2008-2009, 65% of the adolescent population with either private health insurance or the GIP sought ambulatory care. Females aged 15-19 had the higher number of contacts. The most common reasons to seek ambulatory care were pregnancy (22.6%), general symptoms (6.0%), other symptoms involving abdomen and pelvis (5.6%), hypothyroidism (5.5%) and disorders of menstruation (5.0%). The most common reasons leading males to seek care were: general symptoms (9.0%), viral and chlamydial infections (6.9%), other and unspecified disorders of joint (6.3%), Disorders of lipid metabolism (6.2%) and special examinations and investigations (6.0%). Adolescents holding private insurance were more likely to use ambulatory services than those with GIP.

Hospitalizations

Adolescent females between 15-19 years old had the highest rates of hospitalizations. They were six times more likely to be hospitalized than males. Among the reasons for their

hospitalizations were: pregnancy-related diagnoses (88.6%), infections specific to the perinatal period (1.9%), affective psychoses (1.2%), asthma (0.9%) and gastroenteritis (0.8%). The most common reasons for hospitalizations of males were appendicitis (20.5%), cellulitis (14.2%), dengue fever (6.5%), gastroenteritis (5.2%) and asthma (5.1%).

Risk Behaviors

Risk behaviors in areas such as driving, substance use and abuse, physical exercise, diet and sexuality contribute to the leading causes of morbidity and mortality later in life. The Youth Risk Behavior Survey (YRBS) measures the incidence and prevalence of these behaviors. Risk-taking behaviors and teen sexual activity affect the future health of a significant proportion of Puerto Rican youth. This situation is a long-standing concern of a broad sector of stakeholders in the Commonwealth of Puerto Rico. In this section, we intend to describe selected behaviors in which our Puerto Rican public school students (PRS) are engaged in comparison with the U.S. mainland. The description is based on data from the 2005 YRBS.

Injury, Violence and Suicide

Among Puerto Rican Students (PRS) aged 10-19, motor vehicle deaths account for 22% of all deaths. This figure is much lower than the national average (31%).

- 7% of PRS rarely or never use a safety belt, compared to 10% nationally.
- 33% of PRS rode in a vehicle with a drinking driver during the previous month, compared to 29% nationally.
- 26% were in a physical fight the previous year, compared to 36% nationally.
- 9% carried a weapon during the previous month, compared to 19% nationally.
- 15% attempted suicide during the previous year, compared to 8% nationally.
- 6% of PRS have ever been forced to have sexual intercourse, compared to 8% nationally.

Tobacco, Alcohol and Drug Use and Abuse

- 36% of PRS have ever smoked cigarettes, compared to 54% nationally.
- 11% of PRS have smoked cigarettes during the previous month, compared to 23% nationally.
- 67% of PRS have ever drunk alcohol, compared to 74% nationally.
- 39% of PRS had drunk alcohol during the previous month, compared to 43% nationally.
- 23% of PRS reported binge drinking during the previous month, compared to 26% nationally.
- 2% of PRS have ever used cocaine, compared to 7% nationally.
- 1.6% of PRS have ever used heroin, compared to 2% nationally.
- 13% of PRS have ever used marihuana, compared to 38% nationally.

Sexual Behavior

This behavior is associated with unintended pregnancies and STIs among adolescents.

- 37.6% of PRS have ever had sexual intercourse, compared to 47% nationally.
- 8% of PRS have had four or more sex partners, compared to 14% nationally.
- 5% of PRS used oral contraceptives at last intercourse, compared to 18% nationally.
- 24% of PRS had had sexual intercourse during the previous three months, compared to 34% nationally.
- 58% of PRS did not use a condom at last intercourse, compared to 37% nationally.
- 12% of PRS reported the use of alcohol or an illicit drug at last sexual intercourse, compared to 23% nationally.
- 86% of PRS reported they had received HIV/AIDS information at school, compared to 88% nationally.

Adolescent Pregnancy

Adolescent pregnancy is a concern in PR as well as in many other parts of the world. Mass media frequently bring this issue as its headline news. Pregnancy outcomes are composed of live births, fetal deaths and abortions (spontaneous or planned). Since we do not have data concerning abortions it is difficult for the PR MCH Program to collect information about the number of pregnancies in adolescents. Therefore, when we talk about this issue we refer to the proportion of live births among women between 10-19 years old.

Analyses of the rates of births among adolescents 10-19 years old show a significant increase from 1990 to 1997, particularly 1994 to 1995. According to the Average Annual Percent Change (AAPC), birth rates significantly increase by 8.2% from 1990 to 1997. This increase would be a result of the establishment of the Health Care Reform in Puerto Rico that causes a decrease in the access to contraceptive methods. After that, a downward trend is observed, reaching the lowest level in 2003 and 2006 with an AAPC of -3.7 % (Figure II-21). Birth rates in adolescents 10-14 and 15-19 years old also show a decrease between 1990 to 2006 period. According to AAPC birth rates decrease significantly by 2.9% in adolescents of 10-14 (Figure II-22) and 1.4% in adolescents of 15-19 years old (Figure II-23).

In 2006, every day in PR some 24 live births occur in adolescent mothers. Nearly 23% are repeated pregnancies. Eight out of 10 adolescent mothers are unwed. According to ESMIPR 2008, only 24.4% of adolescent mothers plan their pregnancy.

Pregnant teens are more likely to begin prenatal care after the first trimester of pregnancy and to have poor birth outcomes in comparison with women between 20-34 years of age (Figure II-24).

Sexually Transmitted Infections (STIs)

The proportion of PRS who reports ever having sexual intercourse has increased from 28.3% in 2001 to 37.6% in 2005 (YRBS). However, the percentage that used condoms to prevent a pregnancy or an STI also has increased from 33% in 2001 to 42% in 2005. This

risk behavior may explain our rates of unintended pregnancies and STIs among adolescents in Puerto Rico.

Figure II-25 presents the HIV/AIDS cases among 10-19 adolescent group in Puerto Rico since 2000. The number of cases among males and females show a decrease during the period of 2000 to 2008.

Among males the most common routes of infection are intravenous drug use (53%) followed by same-sex intercourse (22%). Girls are most commonly infected through sexual contact followed by intravenous drug use.

Chlamydia is the most common STI among adolescents in Puerto Rico. Its prevalence varies by age group and sex. In 2008, females aged 10-14 and 15-19 are 15.3 and 12.5 times respectively more likely to be infected than males. Among females 10-14 years old, the average prevalence is 32.1/100,000, while in males it is 2.0/100,000. The rate increases exponentially in the 15 to 19 years age group. In this age group, females have an average prevalence rate of chlamydia of 774.0/100,000, while the males have an average rate of 77.1/100,000.

Figure II-26 presents trends in chlamydia infections among adolescents by age group and sex.

Syphilis and Gonorrhea

The incidence of syphilis infections among the adolescent group has been decreasing since 2000 (Figure II-27). In the group of adolescents 10-14 years, the prevalence rate did not change significantly. For adolescents 15-19 years, the incidence declined from 6.9/100,000 in 2000 to 5.3/100,000 in 2008. For adolescents between 15-19 years of age, in 2008 the prevalence was higher among male adolescents (5.8/100,000) than in females in the same age group (4.8/100,000).

In relation to Gonorrhea infections (Figure II-28), the incidence rate in male adolescents 10-14 years was 1.6/100,000 in 2008 and 0.0/100,000 in females of the same age group. In adolescents 15-19 years, the rate was 1.7 times higher in the female group (18.6/100,000) than in the male group (10.6/100,000).

Mortality

During 1990-2006 the mortality rate among adolescents 10 to 14 years of age decreased from 20.9 in 1990 to 12.2 per 100,000 in 2006, with an average of 21.1/100,000 (Figure II-29). The average number of deaths per year is 67 for this group. Death probability for males is 1.4 higher than for females in 2006 (Figure II-30).

For adolescents 15 to 19 years of age, mortality rate also decreased from 75.7 in 1990 to 68.5 in 2006 with a yearly average of 89 deaths per 100,000 (Figure II-31). The average number of deaths per year for adolescents 15 to 19 years of age is 281. In 2006, death probability is 4.5 times higher for males than for females (Figure II-32). Also this group of

older adolescents (15-19) shows a death probability that is 5.6 times higher than the 10 to 14 years group for 2006.

When comparing the principal causes of death for adolescents six decades ago (1950) to the last decades of the 20th Century, we find a considerable difference. During the 1940's adolescents died mainly of infections and biological causes. The main causes of death in 1950's, based on frequency were: (1) infections; (2) external causes; (3) systemic diseases; (4) cancer and (5) maternal deaths. Among the infections we should mention tuberculosis (white plague), diarrhea, pneumonia, and childhood diseases that are prevented by immunization such as tetanus, measles and whooping cough. Anemia, parasitic infections such as uncinaria and malaria; and puerperium (maternal deaths during childbirth) claimed the life of many adolescents. Deaths due to external causes (suicides, homicides) represented only 20% of all deaths among adolescents during the end of the first half of the 20th Century.

In 2000-2006 a total of 340 deaths were reported for the age group of 10-14 and 1,542 deaths for adolescents 15-19 years of age. For adolescents 10-14 years of age death was due to an unintentional injury in 30.9% of cases. The second position for cause of death was malignant tumors (15.0%), diseases of the nervous system occupied a third place with 12.6%, and a fourth place for homicides with 3.2% of cases followed by diseases of the respiratory system with 3.2%. Eight deaths by suicide were reported. In general, 39.5% of deaths for this group can be attributed to external causes such as unintentional injuries (30.9%), homicides (6.2%) and suicides (2.4%).

When considering cause of death for adolescents in the 15-19 age group, deaths due to external causes were 75.4% of the total: homicides (39.9%), unintentional injuries (31.4%) and suicide (4.1%). Another 6.0% of deaths were consequence of malignant tumors and 3.1% due to diseases of the nervous system.

In 1950 morbidity and mortality causes among adolescents were very different to those described at the end of the century and beginning of the new millennium. Back then, most health problems were cared for with antibiotics, purgatives, immunizations, adequate food and good environmental health. At the end of the century, on the contrary, adolescents' health problems were intimately related to social problems that lead to risky behaviors and violence. A biomedical service model is not enough to promote the optimum state of health and well being our adolescents deserve and have the right to.

At the end of the 20th Century and beginning of the 21st, the first cause of death in adolescents was mostly related to violent causes instead of biological causes. Three out of four died of violent causes such as motor vehicle crashes, homicides and suicides.

Magnitude of the Unintentional Injuries Epidemics

Unintentional injuries are not accidents, because they can be predicted and prevented. An unintentional injury is defined as harm to the body due to acute exposure to thermal,

mechanical, electrical or chemical energy; or by absence of the heat or oxygen our body requires.

Unintentional injuries are caused by external circumstances not intended to harm anyone. Roads present the highest risk for adolescents, with alcohol and illicit drugs use and careless and negligent driving as the most important contributing factors.

The most common causes for unintentional injuries in Puerto Rico among children and adolescents (1-19 years) are associated with motor vehicles, poison, drowning, choking, falls and burns.

During 1990-2006 unintentional injuries in Puerto Rico claimed the lives of 2,237 youngsters: 883 in the group of 10-14 years and 1,354 in the 15-19 age group. Our greatest concern is not the number of fatalities, but the thousands of survivors afflicted with handicapping conditions such as trauma to the brain or spinal cord and others suffering lifelong emotional and physical scars. The general public should be convinced that unintentional injuries are not accidents and can be prevented.

For the decades under consideration, unintentional injuries were a significant public health concern in Puerto Rico (Figure II-33 and II-34). They were the first cause of death among adolescents 10-14 years of age and the second cause for death for the 15-19 years group.

Figures II-35 and II-36 show the disparities between males and females in death related to unintentional injuries. Males show a higher risk of death due to unintentional injuries in both age groups. In Puerto Rico, as in other countries, reliable death data for unintentional injuries is available, but we do not know the number of survivors who totally recover or who suffer lifelong injuries. A formula is available to estimate the magnitude of the unintentional injuries epidemic: for each unintentional injury death there are 40 hospitalizations, 1,120 emergency room visits, and 1,600 outpatient visits (Physicians Office).

During the 1990-2006 period, Puerto Rico registered 2,237 deaths among the 10-19 years of age group. If we apply the formula mentioned above to this 17-year period, the estimate of hospitalizations would be 89,480; 2,505,440 emergency room visits; and 3,579,200 physician office visits due to unintentional injuries among adolescents in Puerto Rico. These numbers have an impact on the Puerto Rican society, representing a great loss of school days, years of life, and fiscal resources.

HEALTH INDICATOR SURVEY

Following the analysis of the quantitative data, a Health Indicators Questionnaire was developed and validated to obtain further data from professional stakeholders about the needs of the MCH population. The seven MCH Regional Boards was the unit analysis for this survey. The MCH Regional Boards are composed of multidisciplinary groups of

professionals and representatives from both governmental and non-governmental agencies. These Boards promote coordinated community-based and family centered services for the MCH populations.

The general objective of this questionnaire was to identify, from the perspective of the Regional Board stakeholders, those most important health topics (needs) for each MCH subgroup that should be taken care by the MCH Program.

The specific objectives were designed considering the following factors:

1. Description of the MCH Population (women in reproductive age, pregnant, infants, children and adolescents) needs.
2. Description of formal and informal collaborations to address those needs.
3. Description of strategies and challenges to address those needs.
4. Description of programs or services that work to overcome the identified needs.
5. Description of agencies or organizations that are working or are related with initiatives or interventions to overcome the identified needs.

Based on a list provided in the questionnaire, each participant selected a maximum of three health indicators related with the population of women of reproductive age, two for pregnant women; one indicator related to infants, two indicators related with children aged 1 to 14 and two indicators associated with the adolescent population. If other indicators (health needs) were not listed they could right it on.

To discuss the answers provided in the questionnaire, a meeting was performed in each MCH Region. Through the voting procedure we obtained the indicators with the higher frequency. Also, the indicator with the higher frequency in each subgroup population was discussed in the meeting to collect information of collaborators, strategies, challenges and initiatives or services provided for the indicator. This information was analyzed through the health dialogues included in the qualitative analyses.

About 124 questionnaires were distributed through each MCH Regional Board having a response rate of 59 percent. Approximately, 20% were representatives from non-governmental organizations (private sector) while 80% represent the government sector.

For the women in reproductive age the higher frequency were obtained for:

1. Family Planning (28.8%)
2. WRA with STDs (23.3%)
3. Mental Health (18.2%)
4. Domestic Violence (11.4%)
5. Use of alcohol in WRA (11.4%)
6. Use or no use of folic acid in WRA (6.9%)

The indicators recognized as needs that MCH Program may be address for the pregnant women are the following:

1. Prenatal Care during first trimester of pregnancy (52.1%)
2. Lack of orientations / education during the prenatal care (19.1%)
3. Mental Health (12.8%)
4. Breastfeeding (9.6%)
5. Health conditions (such as chronic conditions: diabetes, hypertension, etc) (6.4%)

For the infant population the following indicators were selected as needs:

1. Immunization (60.8%)
2. Infants with respiratory conditions (10.8%)
3. Birth defects (9.5%)
4. Infants deaths (neonatal, perinatal and posneonatal) (8.1%)
5. Breastfeeding (4.1%)
6. Preventive Health Care (4.1%)
7. Premature births (1.4%)
8. Hereditary problems (1.4%)

Children 1 to 14 years old:

1. Overweight / obese (27.6%)
2. Children neglected and abused (52.9%)
3. Respiratory infections (9.2%)
4. Uninsured children (10.3%)

Adolescents:

1. Tobacco, alcohol and drug use (38.6%)
2. Mental Health problems (32.7%)
3. Suicide and Violence (9.9%)
4. Adolescent Pregnancy (9.9%)
5. Sexual Activity (8.9%)

Strengths and Needs of the General MCH Populations: Qualitative Findings

The concept of need - central in needs assessments -refers to the kinds of problems people experience and the relationship between problems and the responses available (Ervin, 2000). The literature on health and social needs assessment classifies in broad terms two perspectives on needs: normative and felt needs. Normative need refers to what expert opinion - based on experience, knowledge and/or research- defines as need and appropriate. In other words, it refers to a desirable norm or standard set by professionals: service providers, top level administrators, policy makers and/or scientists. Felt needs are the problems, concerns and expectations of people regarding their social and health well-being. That is, what communities, persons and groups say or feel they need (Bradshaw, 1972;

Nueber, 1980). Seeking accommodation between normative and felt needs, we embarked on the task of consulting with both health-related service providers (specifically front-line providers) and beneficiaries or consumers to gain a deeper understanding of their experiences and views on health-related issues. As it was described in a previous section, these views and experiences were obtained through diverse methods and sources.

What issues arose from the health dialogues and other sources of information regarding each general MCH population group? How do stakeholders feel about the issues raised? What strategies and/or actions they brought forward to solve or reduce the problems or needs the target populations face? Key themes and sub-themes emerging from stakeholders' views are presented for each general MCH population groups and sub-groups. In presenting the information a conscientious effort has been made to preserve the way stakeholders spoke and felt about the issues raised. To this end, their "voices" are heard through the quotes cited that appear in the text.

A. Reproductive age women, Pregnant Women and Infants

1. Reproductive age women (10 to 49 years)

There were several concerns and issues raised by health dialogues participants concerning the needs of childbearing age women and the problems they face in Puerto Rico. The findings are provided by themes that emerged from people's comments.

Low or no consumption of folic acid vitamin

A concern expressed by professional stakeholders consulted is the little or no consumption of folic acid among reproductive age women. Professionals indicated that women – adolescents and young women alike - are not using folic acid as it would be expected given the information and campaigns that have been developed throughout the last several years. Interestingly, PRMCH central level staff noted that young men in Puerto Rico are consuming folic acid for the benefits it brings them, especially if they are sport-oriented persons.

What prevents women from using folic acid? Health dialogues participants spoke about the possible factors that may be influencing women's low or no use of folic acid. Several participants claimed that educational information and orientations are hardly reaching women, particularly adolescents. These participants stressed the need to continue outreach efforts after massive campaigns. One participant echoing others asserted:

"We fail by not following up on the information given about folic acid during massive campaigns. It has been shown that it is important to reinforce the information because people really respond well to aggressive campaigns. But once the campaign is over people forget about the issue. We are a country that needs constant reinforcement!"

This participant and others suggested that the Department of Health could carry out what they call “follow-up” campaigns, that is, to reinforce massive campaigns with smaller ones throughout the year. One idea given is to promote folic acid in cinemas where many young women frequently go. Another suggestion is to produce “*attractive posters rich in color*” to draw the attention of women. To develop a campaign similar to the ASSMCA campaign on ‘pregnancy and no alcohol’ was also suggested. To some participants, the ASSMCA campaign is a very simple but effective way to reach women of different ages. The campaign is basically placing flyers (mandatory by law) in visible spots in restaurants, bars, liqueur stores, supermarket and any commerce that sells alcohol beverages. The flyer is also placed in pharmacies and other places even if no alcohol beverages are sold. The message given at the top of the flyer is: “La mujer embarazada nunca bebe sola” (A pregnant woman never drinks alone).

Some PRMCH staff felt that service providers’ interest and commitment has lessened in the last years. They strongly believe that it may be leading health professionals, including those from the Department of Health and PRMCH, to overlook the issue. One staff said with disappointment:

“When we give the message [to professionals] they have the perception that everybody knows everything about the vitamin. Each time we give them training they usually tell us ‘ah, folic acid again’ but they themselves are not clear about the messages.”

Concern was also expressed over the attitudes and responses of physicians toward folic acid consumption as a preventive measure. According to some participants, physicians fail to inform women about the importance folic acid consumption have on their health. On this issue one participant explained: “*We have had meetings with pediatricians but they tell us that they don’t have the time to do prevention. They say that prevention is not their work.*” To some participants there is great need to educate physicians, namely pediatricians, generalists and family physicians, to recommend women to consume folic acid as women tend to listen to them. It was suggested that this could be in their annual conferences.

Women’s own attitudes were also mentioned as impediments to folic acid use. From participants comments there appears to be widespread notion among women of all ages that folic acid should be taken only during pregnancy. According to some participants, women consider they eat healthy and therefore do not feel the need to consume folic acid. On this issue, two PRMCH staff noted that if one asks women about their eating habits, one becomes aware that they are not eating as healthy as they might think. In this respect, it appears that women are unaware that even healthy eating is not sufficient to receive the amount needed to get the vitamin’s benefits.

Erratic or no use of contraceptives

A major key issue raised in health dialogues is the lack of use of contraceptive methods among women, a problem that particularly affects adolescent women, according to the professionals consulted.

When asked about the reasons why women do not use contraceptives, participants mentioned lack of information and limited access to contraceptive methods and family planning services as major barriers. In a PRMCH anthropological study about teen pregnancy and motherhood, school professionals (social workers and counselors) pointed to the need to provide adolescents with family planning services.

Regarding family planning, one staff was highly critical of what she thinks is a tendency among many professionals to focus exclusively on contraceptive methods and their use. To this staff, family planning goes beyond the use of methods and involves awareness and knowledge about women's body. As she pointed out: *"We reduce family planning to using contraceptive methods and forgot that it is more than that. Family planning is talking about the changes in a woman's body. We tell women about the methods but not about the reason behind their use."*

Difficulties in accessing free contraceptive methods distributed by PRMCH through participating pharmacies were brought up in several dialogues. It is to be noted that PRMCH makes contraceptive methods available to childbearing age women to fill a gap in the government health plan. Public officials spoke about the hardships women face whenever a given contraceptive is not available in her hometown pharmacy or if there is no participating pharmacy. While women should be able to receive the service (contraceptives) in any participating pharmacy, the actual practice in some pharmacies is to give preference to women who live in the town where the drug store is located. As one participant said:

"There is a limitation. We don't have all the methods available. If one pharmacy runs out of methods then we must make arrangements with another pharmacy in another town to provide a woman with the methods. Sometimes pharmacies prefer to give the service only to people residents in the town of its location. The doctor [Regional Director] has to intervene on behalf of women for them [pharmacists] to do us the favor to give methods to women from another town."

Another difficulty mentioned is that participating pharmacies may run out of contraceptives supplied by PRMCH in a relative short time. One participant explained:

"The demand is great and the offer low! They [PRMCH] are sending us very small quantities of contraceptive methods. We have to send pharmacies small amounts of methods that in a short time run out. Before the month is over there are no methods available. "

Reluctance of the IPA (medical group) physician to give out prescriptions is also a barrier a woman faces to access PRMCH distributed free contraceptives. This is done, according to participants to push women to buy the methods from the IPA.

Participants in different health dialogues gave the suggestion that contraceptive methods should be included in the government health plan to make them accessible to low-income women.

In regard to adolescents, some stakeholders believe that sexually active adolescent females resist using contraceptives to prevent a pregnancy. These stakeholders were unable to explain why adolescent women do not use contraceptives. The anthropological study on teen pregnancy and motherhood sheds light on this issue. The research findings in regard to the use of contraceptive methods among teen research participants show that: 1) there is a gap between knowledge and use of contraceptives; 2) participants do not use contraceptives or use them erratically; 3) participants are suspicious of contraceptives because they are “harmful”, “they are not safe”, or they “make one gain weight”; 4) their partners often refuse to use condoms. On the whole, the use of contraceptive methods does not form part of the cultural notions and practices among the teens interviewed in this study.

Post partum depression

Post partum depression was cited by PRMCH staff and Regional Board members as an emerging issue of concern. Post partum depression is a serious problem that causes negative feelings and emotions toward the infant and thus, could lead to child maltreatment (physical abuse and/or negligence) and even the death of an infant and the mother’s suicide. Stakeholders reported three main difficulties they have in making referrals to mental health services if they detect (through screening) depression. One difficulty is the rejection of women to seek professional help. In the words of one staff:

“There are many participants who refuse to be referred. They don’t want to be evaluated by a psychologist or a psychiatrist. There is some negativity in seeing a mental health professional because in Puerto Rico mental health is associated to being crazy.”

Programmatic policies of existing mental health services can be impediments to making referrals. According to participants some services require that the woman herself must make the arrangements (call the service and make an appointment) to receive service.

In several health dialogues, participants indicated that ASSMCA currently lacks sufficient contractual mental health service providers to cover the needs of women experiencing post partum depression.

Reluctance to breastfeed

In various health dialogues, participants raised the issue of lack of breastfeeding among women, especially adolescents. Participants pointed to a number of reasons. One reason given is women's unwillingness to breastfeed their infants. In addressing this issue some participants referred primarily to adolescent mothers who have preference for bottle milk over breastfeeding. To some participants, adolescent women refuse to breastfeed their infants because they lack motivation and commitment. One participant strongly felt:

“Lots of adolescents prefer to bottle feed their babies rather than feeding them with maternal milk because it is easier. They think formula milk is thicker, the child does not get hungry, sleeps more, and therefore he/she doesn't bother. When you educate them about the importance of breastfeeding they do it once or twice and then they say ‘I can't get up every hour, I prefer the formula’. There is no commitment at all.”

Contrary to what seems a prevailing idea among participants in several health dialogues, one PRMCH staff highlighted a cultural aspect influencing women's disinclination toward breastfeeding; the pressure exerted by other women in the family (mothers and grandmothers) to bottle feeding. As she remarked:

“They really don't believe in this process. Many families [grandmothers] don't believe in breastfeeding. It was in that generation that the use of milk formula was promoted. Now to return to breastfeeding becomes a generational clash. It is a barrier between one generation and the other.”

Some women staff - mothers themselves - indicated that women may not breastfeed because they are not familiar on how to correctly breastfeed. These women staff recalled the hardships they experienced to learn breastfeeding because hospitals only give information but no concrete tools to new mothers. As one pointed out: *“I was wrongly educated. Each hospital should has a good breastfeeding educator”* These participants suggested the use of doulas in hospitals to educate and train new mothers.

Need for Preventive Health and Empowerment

Some participants brought up the need to address preventive (preconceptional and interconceptional) health care for women. From their comments, women seem to have little understanding of health and may not know when and how to seek health care or how to lead a healthier life. One research staff thinks that there should be guides (similar to pediatric guides) to women's health.

The need to empower women to overcome “fear” of physicians came across most health dialogues. Empowerment as used by participants consulted is to encourage women to ask questions, demand tests, and be more assertive when it comes to their own health and that of their children. On this issue, a participant had this to say:

“We empower and give them tools so they take the courage to ask questions because in our culture we have always view medical doctors as all knowledgeable who have the last word. Many times they [women] are afraid to formulate complaints”

Especially interesting in this regard is that the term “fear” was widely used by stakeholders in their discourses. The notion of fear points to the hierarchical relationship between the medical doctor and the patient. In this type of relation the physician has authoritative knowledge and controls the consultation and the treatment. The patient, in turn, is expected to comply without asking too many questions or raising doubts about the intervention (Fairclough, cited in Craven 2005).

2. Pregnant women

Participants discussed a number of concerns about the health of pregnant women and the difficulties they experience in accessing and/or receiving needed services. What are these concerns? What difficulties they face? Answers to these questions are provided by thematic areas of concern.

Late entry into prenatal care

A common theme that emerged from the health dialogues was the issue of pregnant women, particularly teens, not receiving timely prenatal care or not receiving services at all. In the case of teens, health dialogues participants noted that adolescents, out of fear of parents conceal the pregnancy resulting in late entry into prenatal care. As one participantsaid: *“The fear she has about telling that she is pregnant leads to initiating prenatal care very late, after the first trimester. Since they don’t tell they do not enter care.”*

Adolescents whose parents are subscribed to the PR government health plan (commonly known as the Reform) face certain barriers in obtaining prenatal care on time. Participants indicated that in order for the adolescent to receive prenatal care, she must apply for her own government health plan card. This means the family must remove her from the plan before she can apply. Those teens whose parents have private health care plan, must also apply for government health plan because private plans do not cover teen pregnancy (unless parents pay higher premiums). Physicians will not see teens until they have their own government health plan card or if parents pay for the services. The process of removing the teen from the family health plan to obtain the government health plan card can take time and often results in delayed prenatal care services. As one participantsaid:

“I see medical assistance [government health plan] as one obstacle. If they are adolescents they required the family to remove them from the health plan. The mother has to go in person to remove the daughter from the plan [to enable them to get an appointment] and in all the transactions and the time the mother makes the decision to remove her from the plan, prenatal care is delayed.”

Bureaucratic requirements often hinder the ability of teens as well as adult women to obtain the government health card. According to health dialogues participants, obtaining the government health plan card can be a very cumbersome process. For instance, those applying for the health plan are not always told about all the documents they need to bring and, quite often must travel back and forth between agencies to obtain the required documents. There are women, particularly adolescents, who out of frustration stop this process leaving them with no prenatal care. One public health official put it this way:

“I have this client whom I send to x agency, they send her back to me because she has not this or that paper. The girl gets tire and is left without services. The girl loses her interest because it is like to be a ping-pong ball [going from one agency to another].

Participants in most health dialogues recalled the prenatal care for adolescents before the implementation of the Health Care Reform in the 90's. They explained that pregnant adolescents received all needed services in one site that was of great benefit to the continuity in health care during their pregnancy and after giving birth. To them, these services were far more integrated than those provided today as a myriad of services and professionals were available. One participant commented:

“In the past system the clinics functioned well because teens received all health services during pregnancy and after giving birth – ob-gyn, health educations, one-on-one social work orientations, interventions with families, WIC services and others –in one place”

Participants offered suggestions to promote early pre-natal health care in women: 1) Special health pre-natal health clinics targeted at adolescents and; 2) Coordinate through appropriate channels the services pregnant adolescents need.

Transportation barriers

Low-income women (adults and teens) residing in semi-rural and rural areas face transportation difficulties that may hinder access to and continuity in prenatal care. Low-income women use transportation provided by private certified vans (called “carros públicos” or public cars). These public cars provide transportation services until 2 p.m. or earlier. This limited transportation service poses problems for pregnant women that may have to wait until late afternoon to be seen by a physician. This means that in late afternoon public transportation is not available for women to return home. This may result in missed appointments.

Lack of Ob-Gyn Providers

Women also are not getting prenatal care in a timely manner due to a lack of specialty providers (gynecologists and obstetricians) in many municipalities. In municipalities where these services are available, these can be very limited, for example, a given physician may provide the service once or twice a week only. There are physicians who provide services in three or more municipalities. Due to shortages in health care providers, the point at which women begin receiving prenatal care may come later in their pregnancy.

Some participants reported that appointments may be scheduled 1- 2 months out. Physicians' shortages together with limited transportation also result in missed appointments of women already receiving prenatal care that may adversely affect their health.

A related issue that affects adolescent pregnant women is that ob/gyn services are provided during school hours, which according to participants, results in absenteeism that in turn, affects their grades negatively. Indeed, the PRMCH anthropological study on teen pregnancy and motherhood found that missing school and/or tardiness due to health appointments was the rule and not the exception among research participants.

All the factors mentioned (transportation, service hours, availability of services) can have negative health implications by making women less likely to seek and/or receive prenatal health care. For example, health dialogues participants noted that there are pregnant adolescents that do not receive prenatal care at all and are more likely to go through the hospital emergency room to give birth.

Vaginal infections

Some staff participants expressed deep concern over vaginal infections in pregnant women as they are associated with premature births. According to staff from the Home Visiting and Healthy Start programs, the screenings the visiting nurses perform on each woman indicate that more pregnant women that participate in these programs have vaginal infections. Women are unaware of the types of vaginal infections that could be affecting them. Staff indicated that obstetricians are not doing the necessary tests to detect vaginal infections. *"Women are unaware of the different types of infections that may affect them. Supposedly obstetricians are not ordering the necessary tests to detect infections."* More efforts should be directed at providing pregnant women with adequate information on vaginal infections.

Unduly charges for medical services

According to information provided in several health dialogues, there are physicians that charge pregnant women for services covered by the government health plan. To these participants this practice constitutes abuse against women particularly adolescents.

Need for sensitive prenatal health care

The issue of patient-physician relations was brought up by participants. In some dialogues participants spoke about the need pregnant women have to not only receive information but more importantly that the physician explains thoroughly about any health condition that they may have or how to keep healthy during the pregnancy. However, the general feeling is that physicians seldom take the time to explain and listen to women's doubts. Participants indicated that pregnant women are hesitant to ask questions and solicit tests they need out of *"fear to lose"* the service.

Empowering women also applies to pregnant women as they are also unable to question the gynecologist/obstetrician decisions and/or practices concerning the pregnancy. According to participants, ob-gyns have great control over treatment and procedures related to pregnancies and childbirths including “planned births” that is, induced labor and/or C-Sections. The fear pregnant women might feel toward medical doctors was also addressed in health dialogues. One Visiting Nurse echoing others commented:

“She must take control over her pregnancy. Many times we see gynecologists that think they own the pregnancy! Many times we ask a woman: what the gynecologist tells you? And she tells me, Ah, he did not tell anything. I then ask her: What did you ask him? She says, Ah, I would not dare to talk to him”.

Staff from the Home Visiting and Healthy Start programs further explained that women feel more comfortable with the Visiting Nurse that offers them trust (“confianza”) listens to their doubts, answers questions, and treats them in a humanly way. In this regard, women participants in the Home Visiting/Healthy Start programs expressed the need women have to receive information and support during the pregnancy. As one stated: *“I could clarify all doubts about the pregnancy”.*

3. Infants

Adult stakeholders were asked about the health issues that affect the infant population in Puerto Rico. The key health-related themes concerning infant health from the perspective of adult stakeholders – professionals and parents – are presented in this section.

Immunization Delay

An issue raised in most health dialogues (professionals, mothers, and staff) relates to immunizations. Participants brought up the delays in having infants immunized. Immunizations are vital for the infant’s health and development that could have repercussions as they aged. What might be causing delays in immunizations? Some professionals consulted reason that negligence on the part of parents - who receive WIC or Head Start services - partly determines immunization postponement. As one asserted: *“Many parents lose interest no matter what they are told about the importance of the vaccines. Anyhow they are not motivated to go to immunize their children”.*

Other participants expressed critically that the IPAs often have no vaccines or some of the vaccines available. Many parents in the government health plan seek the service elsewhere for which they have to pay. As one mother recalled:

“Here [referring to the IPA] they practically don’t have all the vaccines for the children. That is why my son had two missed vaccines. The place where I can only get all the

vaccines is [name of town] though one has to pay more. Recently I went to [name of town] when my child was six months old and paid \$20.00 for all the vaccines he needed. I prefer to pay more and go there”.

In this regard, participants spoke of IPA’s practice of scheduling a specific date to immunize infants and children. Generally, in this type of scheduling, a limited number of infants (and children) are immunized. Families generally get there early in the morning but might leave without having received the service. In the words of a public health official:

“There are lots of difficulties...there are pediatricians that immunize ten to fifteen children a day and after that number the remaining get postponed. When families get to the center the number has already been filled and practically they waste their time. Therefore, they never can follow the immunization scheme” .

Public officials explained that pediatricians attending families with private health plans are not immunizing in their offices due mainly to certain requirements they must meet such as having an electricity plant (in the event electricity goes off) and a refrigerator to keep the vaccines. As one Regional Director said:

“The child on the government health plan can go to certain places, the ones with private health plans must go to their pediatricians. The greatest problem we have is those little patients who have private plans. Many pediatricians have no vaccines available because they are costly. When these children go to a provider that has the vaccines from the Department of Health they cannot administer the vaccines because it constitutes fraud since they are paid by federal funds. These federal funds forbid to immunize children with private plans. Responsible parents seek the service to no avail”.

These families, participants explained, do not qualify for the services provided by 330 Centers (Primary Health Centers) if their plan covers the vaccines. They only qualify if the 330 Center combines federal and state funds. There are centers administered by the Department of Health (known as Centros Calderón) that do take private plans. Moreover, if the private health plan does not cover the vaccines or some of the vaccines parents are required to bring a certification from their respective insured plans. To avoid going through the health plan intricacies, parents might tell the Centers they have no plan at all.

Participants repeatedly and consistently drew a comparison between immunization services before the Health Care Reform and the present. They strongly affirmed that in the past the Department of Health was totally in charge for immunizing the infant and children populations whose needs were better served. Many participants reminisced how nursing staff from the Department of Health used to go to schools and other places for massive vaccinations. The vaccines were available to every infant and child and the nursing staff used to go to schools and other places for massive vaccinations. As one recalled: “We

used to immunize one hundred or more children on a given day. Now the IPAs can't immunize even 30 children." Presently, the PRDOH Immunization Program major responsibilities are buying, storing and delivering vaccines to vendors that immunize children under the government health plan, and monitoring and auditing immunization services.

To address immunizations delays participants strongly feel the Department of Health should carry out campaigns to remind parents about the importance of vaccines. It was also suggested that information of where to go to receive the service should be given parents with private plans. The Health Department should publicize and promote the use of the government administered centers (Centros Calderón).

Respiratory conditions

A health problem mentioned in health dialogues are respiratory conditions such as bronchiolitis and bronchitis. An participant said: *"There are health conditions, we are seeing many children with bronchiolitis, many babies four to six months old"*. On this issue, some participants expressed deep concern about how prepared emergency room physicians are in treating infants. In a health dialogue with Regional Board members, a public health official admitted that the education and orientations perinatal nurses (PRMCH) offer to post partum women in hospitals do not include respiratory tract conditions. To this participant and others, this is of great concern because first-time mothers ("primerizas") *"do not know what to do"* in the event the infant presents respiratory problems.

Several suggestions were made to address this problem: 1) provide community orientation and education; 2) provide pregnant women in the last trimester with education and information about respiratory tract conditions; 3) include respiratory tract conditions in the education and orientations given to post partum women in hospitals; 4) Provide orientations (even courses) to beneficiaries of WIC and Head Start; 5) Train professionals such as teachers on how to manage emergencies related to respiratory tract conditions; and 6) Train emergency room physicians on treating infants.

Limited Pediatric services.

A barrier face by families of infants is lack of sufficient pediatric services, particularly in rural areas or municipalities. In each Health Region, there are municipalities where pediatric services are not available, which makes families to seek services in other municipalities within and outside a Health Region. On the other hand, in municipalities where pediatric services are available, these can be very limited, for example, the pediatrician only sees patients once or twice a week only. A spouse of HV committee participant gave the following account of his experience:

"I got up, you know, around four o'clock in the morning. I was the first to arrive and when I got there she [pediatrician secretary] said, Ah the doctor gets here around 9:30 a.m. I return home and when I got back to the office she [secretary] told me, look the pediatrician is in another town today. You have to go to [name of town]".

Long Waiting Hours to Receive Service

Long waiting hours in pediatrician offices was brought up by both professionals and mothers consulted in the needs assessment. Although appointments are made for a specific date, infants (as it is common practice in direct health care in Puerto Rican society) are seen on a first-come, first-served basis. Generally, parents arrive at the office very early in the morning about 6 or 7 am to write down their names on a list posted in the entrance door. Pediatricians in turn, might arrive past ten o'clock which means that infants and their parents arrive early in the morning but leave late in the afternoon. One has to consider that in many municipalities in Puerto Rico there are shortages of pediatricians. The accounts of several mothers represent common experiences with pediatric services. As one recalled:

“One has to write down the name on the list at seven o'clock when they open the office. But the pediatrician can arrive anytime between eleven or twelve noon and even later around one o'clock. Sometimes I make number 20 and I end up leaving this office between four or five o'clock in the afternoon. The pediatrician is only in the office Tuesdays and Wednesdays”.

Transportation barriers

Participants mentioned transportation issues as barriers to access pediatric services. Many low-income mothers and families rely on public transportation in order to receive health care services. In many PR municipalities, especially rural areas, where mass transportation is unavailable, residents must rely on private transportation services (12 passenger vehicles called “carros públicos” (public cars) in order to access health care services. In many areas, public cars are not available after 2 pm or even earlier. Limited transportation hours could result in postponing the service if the family waiting time extends beyond the limits to return home.

One stakeholder suggested that local officials (mayors) could follow a model of public transportation in rural areas established in one municipality in Puerto Rico.

Inadequate feeding

A number of stakeholders noted that babies (infants) are being wrongly fed. These participants gave examples of wrong feeding like putting sugar in the milk or giving sodas to the infant. *“Babies are overfed. Mothers put solid foods such as rice grains into their mouths”.* One stakeholder pointed to the need of infants for loving tender care which parents often misinterpret. As she said:

“The baby has emotional needs and simply needs to be held and caressed. Mom and Dad give the baby a bottle of milk to have him stop crying. The baby does not necessarily cries because he/she is feeling hungry. It is a matter of holding the child and rocking him up”.

Several suggestions were made to promote healthy feeding of infants. One suggestion is to distribute brochures and other educational materials on healthy nutrition in pediatricians' offices, other services and health fairs. However, a participant was quick to point out that many families seldom read the written materials that are distributed in health fairs and

other activities because “*there is more interest in the little presents (incentives) given than on the information offered*”.

Some participants strongly believe that the government must exert pressure on the beneficiaries of certain public services to participate in educational workshops. These participants highly recommend that families should be obliged (required) to attend educational activities for them to receive a service.

Participants also expressed concerns about infants not being breastfeed. To participants breastfeeding is the best prevention method or at least the best method to prevent or minimize health problems during infancy. Breastfeeding is also critical for bonding. Fostering breastfeeding greatly determines in maintaining good physical and mental health.

Participants in different health dialogues feel that groups of trained doulas can take on the role of orienting and educating women before and after birth.

Need for pediatric preventive health care

One theme that recurred in the health dialogues is the need to promote pediatric preventive health. Participants indicated that pediatricians – despite the pediatric guides – are not providing preventive health care to infants and small children although these services are covered by the government health plan and private plans. According to participants, lack of preventive pediatric health care is largely due to common view among parents and physicians that one only takes a child when she or he is sick. One stakeholder indicated: “*The way I see, it is like a cultural vision of physician-disease and not physician-prevention that also educates. The vision in our culture is that one only goes to the medical doctor when one is sick*”. One stakeholder spoke about how pediatricians themselves may well be barriers to preventive infant (and child) care. On this she stated:

“One of the difficulties one encounters regarding screenings is that appointments are given or at least families are instructed to see the pediatrician only when the infant has a condition or is sick. It is not routine to know about the infant’s development. Our pediatricians are not giving out preventive appointments! Infants must be seen only when they need vaccines or when they get sick or have an adverse reaction to the milk formula. There should be preventive appointments to evaluate whether the child is adequately developing. There are established guides and protocols”.

One Regional Director spoke of her experience with families. She vividly recounted:

“The pediatric guide is not been followed, not even for those children on the government health plan. I ask mothers, does the pediatrician saw the child at six months? No, a mother answers me. And then I said: But when do you take the child to the pediatrician? Well, when he gets sick, the mother answers. And I tell her, have they told you to take the child to the pediatrician? And she tells me No, he [pediatrician] told me the baby is fine, he told me to bring the baby when sick”

Participants indicated that pediatricians may question parents if they show up for a preventive visit. In a health dialogue with mothers of infants, participants mentioned that pediatricians are not checking up infants as they should. Some mothers pointed out that they must “*insist on having the pediatrician check up everything about the infant*” but generally the physician pays no attention to the mother’s request. One mother stated emphatically:

“Sometimes I had been forced to discuss [with the pediatrician]. One tells him the baby has this. He tells you that everything is normal or he tells you that there is no need to refer him for X or Y reason. For example, I asked him if he could do a sugar test because my other children are predisposed to diabetes since my husband’s family members are insulin diabetics and my father’s family also are insulin diabetics. He told me that this couldn’t be done because he would have to puncture [“puyar”] all children. Sometimes he explains everything clearly but other times he is confusing”.

Especially interesting in this regard is that some mothers that participated in a health dialogue expressed concerns about the pediatrician office space that to them could be potentially harmful to the health of their infants and/or small children. As one mother described:

“The waiting room is small and many sick children get there and there are mothers that do not discipline the children even so they are sick. They [sick children] get close to other children and one tries to keep them from touching one’s child”.

This concern of contact with “sick children” could have adverse repercussions for promoting families to seek preventive pediatric health.

Suggestions offered by participants in the health dialogues included: 1) Educate parents on preventive health; 2) Inform parents that preventive health is covered by health plans; 3) Promote pediatric preventive health guides among pediatricians and; 4) Empower parents about their rights and assertive ways to solicit services.

Premature infants

Professional stakeholders showed concern over premature infants. Prematurity have life-long consequences including learning disabilities and developmental problems. Although premature infants need special care and referrals, participants commented that physicians are not doing this work. Participants expressed great concern about induced births (or what they call “physician planned births”) at 36 weeks. Participants commented that many physicians understand that a 36 week birth is not premature.

The suggestions made to address the problem of premature births are: 1) Emphasis must be placed in prenatal care; 2) Promote preconceptional health among women; 3) Address vaginal infections in pregnant women through prevention and information.

Unduly charges for health-related documents

In some health dialogues, participants spoke about unnecessary charges to families with the government health plan for documents such as ‘immunization paper’. In this regard, participants also mentioned that physicians tend to not give families a receipt for services including documents. One participant suggested the Department of Health to put a sign that reads: “*there is no charge for documents or certificates*”.

B. CHILDREN AND ADOLESCENTS

1. Children (1-14 years)

To begin discussion about the needs of children, first it should be noted that some problems identified for the infant population also apply to this population. As these problems were already discussed, suffice is to mention them: limited pediatric services, long waiting time to receive services, transportation barriers and lack of preventive health care.

Deficient Oral Health

Representatives from Head Start indicated that dental caries affect greatly children attending the program. The problem with caries is due largely to children’s intake of sugary foods. These participants also explained that parents fail to take their children to see the dentist. One staff reported the lack of pediatric dentists to tend to the oral health needs of children. She pointed out that parents need information and orientation on oral health and the importance of sealants. To this staff most probably parents are not aware of sealants. While this staff and Head Start representatives in Regional Boards regard oral health important this was not a topic that drew the attention of other health dialogues participants.

Unhealthy eating

Stakeholders involved in health dialogues brought up inadequate or unhealthy eating in children. Childhood eating is characterized by an increased consumption of saturated fats, sugars and salt that has serious consequences for the health of children.

A frequently cited issue related to nutrition is childhood overweight and obesity. In most health dialogues participants spoke about childhood obesity as a very serious health problem in our society. Participants showed great concern about the health implications of obesity – diabetes, and heart diseases. Participants see this problem in connection to inadequate eating habits and lack of physical activity among children. Women in our society, according to participants, are not adequately informed about healthy childhood eating, claiming that inadequate nutrition often begins in infancy as “*many mothers feed infants with bottles full of coke*”. Taking children out to eat in fast food restaurants is a common practice in Puerto Rico.

The role of grandmothers was mentioned as a negative influence in childhood eating. One participant echoing others said:

“There are problems with grandparents. You give information to mom and dad about healthy snacks and the importance of not letting children eat candies. When the child goes to the grandmother’s home, the grandmother says [to the mother] how come you are not going to give candies to the child? Look, the child is too thin, are you sure that you give him enough food? Chubby kids are seen as healthier. The more fleshy tissue they have the healthier they are seen”.

Participants mentioned that by allowing children to watch television and play with electronic devices (internet and video games) for long hours, parents foster sedentary styles of life. The lack of physical activity in children is also a determinant factor in childhood overweight and obesity.

Anemia is a health problem related to poor nutrition, but few stakeholders mentioned it when speaking about children’s health. Representatives from Head Start that participated in health dialogues indicated that anemia is one of the prevalent conditions affecting the children enrolled in their program. In the health dialogue conducted with members of the Healthy Start Program Consortium, anemia was also seen as one of the most serious problems in children.

Altogether stakeholders offered the following suggestions to prevent childhood obesity and anemia: 1) Improve childhood eating; 2) Educate parents about healthy eating and: 3) Promote physical activity in children and families (overweight and obesity).

Need for Healthy Socio-Emotional Development

In virtually all health dialogues with health professionals (staff, members of regional boards, and the Healthy Start Consortium) the socio-emotional development of children was an issue of great concern. The foundations of health are laid in early childhood and limited or no emotional support has negative repercussions on cognitive and emotional functioning throughout an individual’s life.

Mothers that participated in health dialogues and program evaluations of the Home Visiting/Healthy Start programs indicated that families need to have information and education on how to better raise children. To them, one of the most salient effects of these programs on their lives has been *“learning about children’s growth”* and becoming responsible mothers.

Socio-emotional development is directly related to mental health and as stakeholders commented, depression, deficit attention, suicidal ideas and attempts are conditions children are experiencing in present day society. One mental health professional explained that depression affects children as little as 3-4 years of age while suicidal ideas or attempts affect largely children 8 years of age and over. Some participants also expressed great concern for over sexual behavior in children of different ages.

It was indicated that many children live in family environments characterized by violence in its different forms – unhealthy childrearing practices such as screams, threats, obscene

words used to discipline children. Domestic violence also affects the mental health and socio-emotional development of children. One participant had this to say:

“A child living in a family with no good mental health, this family is unable to give the child a good example of how to deal with situations in a correct way. If the child always sees that the family members often shout at each other, use aggressive gestures and raise their fists, they [children] will most likely perceive the world in a twisted way. When you go out you see mothers who scream at the small children, threatening them to ‘break their faces.’ The child’s socioemotional health gets adversely affected”.

One participant pointed out that parent-generated violence is also manifested in sports activities where children participate. Another participant stressed that quite often school teachers face parents with “*extremely aggressive attitudes*” when they are called to the school. Some participants commented that many parents devalue their children by calling them “*idiots*,” “*stupid*”, or “*you do everything wrong*”. Demeaning words have adverse effects on a child’s self-esteem.

While mental health is seen as a serious issue mental health services are extremely scarce for children. ASSMCA has little capacity to tend to the needs of cases in Puerto Rico.

Suggestions made by participants include the following: 1) Family education on children’s developmental stages; 2) Focus more on positive childrearing practices; 3) More resources for mental health providers; 4) Address sexuality in elementary school, and; 5) Address sex taboos in parents

Asthma

Asthma was identified as a problem affecting children who attend Head Start. This problem was also mentioned by Healthy Start participants as one of the health conditions children have. Spouses of Healthy Start women participants also identified asthma as an issue of concern. One staff reported that the quality of life is adversely affected – physically and psychologically (constant fear of not getting air to breath). The same staff explained that all asthma medications are available through the government health plan but physicians seldom give prescriptions due mainly to capitation as they generally face economic losses because medications are very expensive.

Unintentional Injuries

Despite being the leading cause of deaths in children unintentional injuries were overlooked by stakeholders involved in health dialogues. According to central level staff that raised this issue, not only unintentional injuries cause deaths, but they have also devastating consequences for survivors. This staff suggested that perhaps a campaign similar to the “No Tiros al Aire Initiative” - which was designed and implemented to decrease injuries and deaths due to random shots in the air during Christmas festivities – could be designed for unintentional injuries. This type of campaign could be implemented during summer season, particularly about drowning and the use of four track vehicles among children (and adolescents).

2. Adolescents (10-19 years)

What issues specific to adolescents are major concerns among adult participants of health dialogues? How adolescents feel about certain issues? The key themes that emerged in the needs assessment regarding the adolescent population are discussed below.

Teen Pregnancy

A majority of health professional stakeholders regard teen pregnancy as a serious public health problem with many adverse effects on the health and social well-being of mother and child. Noteworthy, most participants who brought up teen pregnancy as a serious issue paid strict attention to female teens. To participants, teen pregnancy is the outcome of risky sexual behaviors among adolescents such as unprotected sex. Despite being active sexually, adolescents feel invulnerable and their pregnancies are mostly unplanned.

School social workers and counselors that participated in the teen pregnancy and motherhood anthropological study (referenced in Qualitative Methods and Data sources in Section 1) raised the point of loss of values in society as a major factor influencing teen pregnancy. They noted that female teens of the present generation have far less restrictions placed on their social behavior and many are allowed to go to places with friends of both sexes and/or boyfriends. To these professionals unrestricted behavior characterizes female teens in present Puerto Rican society.

Health dialogues participants commented that teens are unprepared emotionally and socially for motherhood. Social repercussions include low socioeconomic status, dependency on government assistance, repeated pregnancy, and leaving school. As one participant expressed:

“I am very concerned about the adolescents [mothers] who remain in this cycle that they have their babies and don’t study anything. Few continue studying; they always stay in the poverty cycle. The word for that is conformist”.

It became clear from people’s comments that teen pregnancy is seen as tragedy by professionals in the health and social fields. This vision contrasts the views expressed by the teen research participants in the anthropological qualitative study on teen pregnancy and motherhood. These teens who were pregnant and/or mothers did not perceive pregnancy as a problem. To them pregnancy is *“something that just happens”*. For these adolescents, motherhood has a positive meaning and most of them try very hard to comply with the expected social maternal role. To them being a mother means *“maturity”* and implies *“making sacrifices”*. Contrasting notions of pregnancy and motherhood between health professionals and teens often result in fruitless interventions and messages. PRMCH is now taking teens views as a basis to assess its messages and interventions in order to be culturally appropriate.

On the topic of teen pregnancy, suggestions made by students that participated in Youth Dialogues (2006-2008) include: 1) Provide teens with information on contraceptives; 2) Make information on contraceptives available in school libraries; 3) Bring teens who have

gone through the experience of pregnancy and motherhood to give their testimonies; 4) Use of audiovisual materials and; 5) Continue doing youth dialogues.

Adult stakeholders offered these suggestions: 1) Educate youth on family planning; 2) Incorporate into the interventions the WHO (World Health Organization) guide on abilities for leading a healthy life; 3) Foster female teens to remain in school and; 4) Foster values.

Uninhibited sexual behavior

In most health dialogues, adult stakeholders indicated the need to address the sexual behavior of adolescents characterized by promiscuity. Participants feel adolescents in today's society lack values like respect. The words of one best illustrate their views:

“There is this population [adolescents] whose great majority is unrestrained. They are having all kinds of sexual relations without protection, without knowledge. There is no respect, no guarding oneself”.

Participants attribute adolescent uninhibited sexual behavior to the media influence: internet, movies, TV, radio and music. As one participant said: *“The means of communication such as television and radio encourage promiscuity. In advertisements you see almost naked women. Everything is sexual”.*

Some participants expressed strong criticisms to abstinence programs and campaigns since they are not effective in preventing at risk sexual behavior and teen pregnancy. Adult stakeholders suggested the promotion of responsible sexuality in the adolescent population.

What adolescents have to say about sexual behavior? Adolescents (in activities and research) indicated that curiosity, experimentation, peer pressure, love, and boyfriend's or girlfriend's pressure, are major influences on their sexual behavior. They make the point that either the male or female initiate the sexual relationship.

The study about the cultural perspectives of teen mothers and pregnant teens revealed that female adolescents who are not sexually active can be socially stigmatized by their peers. As one teen commented on how a female adolescent feels: *“Not having sexual relations is like being the ugly girl. Those girls who have no sexual relations are out”.*

Female adolescents are not the only ones to be stigmatized for not engaging in sexual relations. Male adolescents also face the stigma of their maleness being questioned unless they have sex. Quite often female adolescents are the ones exerting pressure on the male and accusing him of not being a man. One professional stakeholder told stories of male adolescents that often tell him how impossible it is to say no when they are pressured to have a sexual relationship. As he said: *“They tell me, mister even so I do not want to have sex I can't say no because they will say that I am gay. I do it for them to know that I am a man!”.*

Adolescents involved in the youth dialogues (2006-2008) suggested adults should talk more openly about sexuality. They also indicated they feel more comfortable asking

questions and making comments in activities attended by small groups. Another suggestion they made is to develop workshops on sexual health targeted at parents.

Mental Health

In most health dialogues, participants mentioned mental health as a serious issue in the adolescent population. Suicidal ideas, suicidal attempts, depression and low self-esteem are serious problems affecting the adolescent population in Puerto Rico. Health dialogues participants from the mental health field explained that Law 408 establishes the right of youth to receive mental health services up to six visits without parents' authorization. According to professional stakeholders the factors that impede the use of mental health services among adolescents are: 1) Insufficiency of mental health services for the adolescent population; 2) The Administration of Mental Health and Anti-Addiction Services known as ASSMCA (Spanish acronym) lacks the capacity to meet all the mental health needs of this population; 3) The Department of the Family laid off psychologists that provided services to families; 4) Adolescents' ideas that mental health services are for crazy people and; 5) Lack of awareness among adolescents of their right to receive mental health services without their parents and/or legal guardians permission.

Some of the suggestions made by stakeholders are: 1) Education and campaigns about available services and; 2) Education and campaigns about youth rights to receive mental health services.

Interpersonal violence

An emerging need felt by youth participating in the PRMCH Youth Health Promoters Program is interpersonal violence in the adolescent population. For the last several years, and as part of the evaluation process of this program, participants have been filling out a questionnaire containing open-ended questions including the following question: What are the most serious problems in your school? A majority of participants in the program have consistently identified "student fights" or "fight between friends" as one of the most serious problems affecting the schools they attend.

More recently, a group of youth health promoters from three different schools said – in a health dialogue - that fighting both in school and in their respective communities is a serious issue. They indicated there is a "*lot of pressure to provoke fighting*" in the school setting. On this pressure one youth commented:

"Whenever you have a problem with another person and they want you to fight with that person they start shouting many things at you. They pressure you to hit the person. You think, I am not going to let them tell me those things... I better hit".

According to youth stakeholders fights occur due to conflicts caused by "*jealousy, gossips, and mockery*". Most of them feel that one should not provoke fighting but it is alright to defend oneself if attacked. Echoing others one said:

“Obviously you have your right. You are going to make them respect you. I can be the Pope’s sister but if someone hits me I am going to hit her or him back. One has its own boundaries and many persons exceed those boundaries”.

Suggestion made include: 1) Tools for handling conflicts; 2) Tools to manage anger; 3) Avoid provocations and: 4) Being a role model (youth health promoters).

Respect for youth

Stakeholders that work with youth strongly expressed the need adolescents have to be respected and listened to. To these participants adults tend to devalue the adolescent population by demeaning and/or ignoring their potential capabilities. Some participants spoke about the adult prejudices toward youth that becomes manifested in thinking and speaking about them as “troublemakers”.

In this respect, youth stakeholders consulted in this needs assessment urge adults to stop judging them and instead recognize what adolescents have to offer society. As one youth health promoter emphatically said:

“They should seek groups like ours that give all the potential we have. We don’t give 100 percent we give 150 percent to achieve our goals. They should not be looking only at those that say I am going to leave school” .

PRMCH staff - from Central and Regional Levels – that work with adolescents emphasized Positive Youth Development (PYD) as the best philosophy and strategy to promote youth health. Positive Youth Development is a strength oriented approach rather than deficit oriented and engages adolescents as active participants in their own development and that of their communities. Generally, professionals in the health and social fields treat adolescents either as problems that must be told what to do and how to behave; the adolescent being a mere recipient of program policies and activities.

Positive Youth Development also means treating youth with respect as contributing members of society. Interviews with program participants of a pilot PRMCH initiative - in a Social Treatment Center of the Administration of Juvenile Institutions - reveal the importance respect has for participants. The adolescents interviewed highly value the respectful way they were treated by program staff that always considered their views and allowed them to make decisions concerning program activities. As one youth told with admiration:

“She is a person [referring to coordinator] that gives advice and listens patiently without judging. She and the others always respected our opinions. We learn how to listen to one another respecting each other opinions without using negative words. We made decisions together, talking, without verbal fights”.

Positive Health Messages

Some participants stressed the need to use positive messages to address at risk youth behaviors – drug use, smoking, unprotected sex and others. To these participants the tendency to give prevention messages in negative and scary ways may actually have an opposite outcome to what they are trying to prevent. These participants strongly advise to develop prevention campaigns with positive messages.

Concluding Remarks

The preceding section has documented the ways stakeholders consulted – professionals and beneficiaries alike - in the needs assessment perceive and assess the health needs of the general MCH populations.

A number of issues emerged that affect two or more general MCH population groups. First, very limited public transportation, particularly in rural areas, hinder access and/or continuity of health care services. Second, access to medical care is very limited due to shortages of specialists in municipalities. Third, all general MCH population groups spend excessive time in the waiting room to receive medical services. It is not uncommon for families to wait more than four hours to receive health care services. Fourth, preventive health for reproductive age women, infants, children and adolescents is an emerging critical health issue. Finally, environments conducive to social and emotional well-being is also an emergent necessity. We have seen that depression affects small children, adolescents and women.

Running tandem with these health issues, violence severely affects people in this society and seems to have become the norm in social relations. It became clear from adolescents assessments that violence is an important issue for them. For several years participants of the Youth Health Promoters project have been asked to mention the most serious problems they face in the school setting. Adolescents consulted have been reporting “fights” as one of the most serious problems they face in school.

As it was indicated in the discussions of teen sexual behavior and pregnancy most probably establishing sexual relations during adolescence is a cultural norm (ideal or expected behavior) among Puerto Rican youth. Puerto Rican society has been experiencing social and cultural transformations including those related to sexuality and affective relationships. In present day society, children and adolescents are socialized in a cultural context that is generally – especially in regard to sexuality – very contradictory and ambiguous. Younger generations tend to view sexual relations as something more natural than previous generations. These are changes that adults of older generations find it difficult to acknowledge much less consider for interventions. New forms of cultural norms and behaviors are often dismissed as loss of values.

As it was described previously, teen mothers that participated in the Pregnancy and Motherhood anthropological research do not regard teen pregnancy as a major problem or tragedy. The study findings concur with teen pregnancy research in Latin American,

United Kingdom, and the United States that found that teens do not attach negative connotations to pregnancy and/or motherhood. This is suggestive of the complexities of pregnancy and motherhood in the adolescent population and that interventions and prevention messages given need to be revised and refocused if necessary. Presently, the PRMCH through the Bayamón Health Region, the research site for the Pregnancy and Motherhood study, is taking steps to revise the interventions in order to make them culturally appropriate considering the cultural norms and beliefs of the younger generations.

The information gathered also point to a serious need for health literacy in the MCH population. Health literacy refers to the capability of people to request, process and understand basic health information. MCH populations particularly those from low-income sectors generally lack the appropriate health literacy tools. However, one must go beyond health literacy to include empowerment of individuals and communities. Empowerment for health refers to the process of gaining greater control over decisions and actions affecting health. In connection to the physician-patient relationship, it means overcoming “fear of medical doctors” and knowing what to do in case a physician reacts negatively or simply ignores requests for tests and/or questions people may have regarding treatment or procedures.

Concerns and uncertainty about the future of public health was a consistent feeling among a majority of professional stakeholders. To them, the public health system “is no longer public” as many services have been privatized and those that still remain within the public sphere could be privatized as well. These stakeholders have witnessed a myriad of problems brought about by the 1990’s health care reform. The fragmentation of services, loss of primary health care functions, and capitation are resulting problems. To participants the past public health system, despite its shortcomings, was far more integrated than the present one.

The qualitative information collected in this needs assessment point to certain health issues that should be explored further. A topic that deserves examination is women’s concept of health, disease and health care for themselves. Women in Puerto Rican and other societies play the gender assigned role of caring for the health of others: their parents, children, husbands or partners. In this connection a question arises: How does this role affect their health behavior?

Another key area that deserves closer examination is women’s prenatal care beliefs and practices. PRMCH pays attention to women’s initial entry into prenatal care and information and education receive during pregnancy. Little attention, if any, is given to the cultural aspects of prenatal behavior. Reproductive health and activities around pregnancy and motherhood are greatly influenced by social and cultural factors. Paying attention to these factors will be of great help in designing most appropriate health messages and interventions.

It will also be important to ascertain women’s perceptions, feelings and actual breastfeeding practices and the factors that influence those beliefs. In this regard, the way

women kin (mothers, grandmothers, aunts and others) exert influence on whether to breastfeed or not should be a focus of attention. Ideally, women kin should also be involved in the promotion of breastfeeding as women generally are surrounded by a network of relatives.

Another area to consider are women's views on contraceptive methods and experiences seeking family planning services including the contraceptives distributed by PRMCH.

Very importantly, it is critical that the views of male youth are better understood with regard to sexual behavior and contraception. Their voices still need to be heard and incorporated into interventions since the issue of masculinity is at the center of male sexuality.

It will also be instructive to pay attention to the concept of femininity in the younger generations and its influence on sexual behavior. In some youth dialogues, participants mentioned that females may fear being regarded as "not liking boys" if they refused a sexual encounter. In this regard it is important to consider the cultural norms, beliefs, and values of the younger generations. As stated above, Puerto Rican society has been experiencing social and cultural changes that need to be considered in health interventions.

4. HEALTH SYSTEM CAPACITY

For 2008 the MCH population comprised 49% of the PR Population (1,937,412 of 3,954,037). Specifically, 28.5% (1,126,490) were women in their reproductive age (10 – 49 years old) and 20.5% (810,922) were children 0-19 years old in Puerto Rico. The Population Estimates revealed that the level of poverty was 45.5%, while 41.1% of families were under the poverty threshold. Among the PRCS participants in 2008, 99% responded they considered themselves Hispanic. The major ethnic groups reported as living in the Island were: Puerto Ricans (95.6%), Dominicans (1.8%) and Cubans (0.5%). According to the 2000 Census and 2008 PR Community Survey (PRCS) data, white race predominates in PR. However, we are certain that the information under race classification reported in the PRCS and the Census is biased for two main reasons. First, the question does not include other racial categories used by Puerto Ricans. Second, there is a social stigma attached to being black among Puerto Ricans. Nevertheless, there is not a significant disparity in race in the Island. For this reason, we will not make a distinction by race when describing the MCH population.

Improving the health status, well being and quality of life of the MCH and their families is a great challenge for the MCH/CSHCN programs. To achieve this goal it is imperative to develop and implement a concerted action plan among a diversity of public agencies, private entities, and community-based organizations, with the involvement of the families themselves. This is so, because there is not a single public or private entity with all the resources and capability to address by itself the multiple and complex socioeconomic and health needs of the MCH population.

On the other hand, the current government has adopted drastic measures to deal with the financial crisis in the Island. Law No. 7 of March 2009 mandates among other measures, the reduction of governmental budget by elimination of personnel in transitory positions and those permanent positions with less than 13 years in the workplace. This represents more than 30,000 jobs. Reorganization and consolidation of government agencies is the first step for this Government. This restructuring also affects the Department of Health and their collaborators.

The unemployment rate increased to 16.0% in 2007, a 1.9% of increase when compared to 2006 (15.7%). In May 2009, the labor force in PR was estimated at 1,335,000 persons, of whom 1,143,000 were employed and 191,000 were unemployed. If one compares these figures to those in May 2008, there has been a decrease of 76,000 in the number of persons employed. This reduction has been accompanied by an increase of 35,000 persons that have joined the unemployment ranks. This means that the annual changes brought about a reduction of 40,000 persons in the labor force and many of them will be persons searching for health care services provided by the public agencies (Government).

Health Care System and Direct Services

In this section we will describe the offer of health services particularly those targeted at the most needy of MCH populations, low-income people that receive the Government

Insurance Plan (GIP). We will also describe the changes that are occurring in the Health Care System (HCS) in Puerto Rico since 1990 from a health services provider to a privatized managed care model, contracting the health lending. The goal of this new model is to enhance the quality and accessibility of health services to the population. This includes the capacity of the system to provide or assure the availability of direct health care services for the MCH population.

The philosophical concept of Manage Care was implemented without studies relevant to the needs of the population who were to serve. The primary concept of that service delivery model was to reduce the economic costs making health services more efficient. The results obtained have not filled these expectations.

Traditionally, the HCS in PR was divided into two parallel systems, public and private sectors. The public sector was responsible for addressing all health care needs for almost 60% of the population, low-income or uninsured population. On the other hand, the private sector served approximately 42% of the population who could pay out of pocket or through third party payers.

The Puerto Rico Department of Health (PRDOH) historically functioned as the predominant provider of personal health services for low-income and uninsured populations. It operated through an extensive regionalized network of level one primary health care centers, at least one in each municipality; areas' hospitals (level II); regional hospitals (level III); and a Supra-tertiary Center.

Over the years, PR Medical Assistance Program only paid for hospital-based services, including in-patient and outpatient care for categorically and medically needy persons. Because of this, Title V funds were used as the first payer for ambulatory care services for women in their reproductive age (family planning, prenatal and postpartum services), preventive services for children and specialized for CSHCN.

High-risk pregnant women and children were referred to Regional Hospitals for follow-up. These referrals pose great difficulties for the patients since they had to travel a distance from their residences to the Regional Hospital for an appointment. As an example, a high-risk pregnant women living in the Municipality of Orocovis had to travel about 38 miles (one trip) in public transportation to reach the high-risk prenatal clinic based at the Bayamon Regional Hospital. In addition, due to the limitation of staff at Regional Hospitals and the high number of referrals the follow-up was not given according to the patient's condition. Other reasons for referrals to Regional Hospital were for laboratory and X-rays services. Children with special conditions ran the same luck as their mothers.

In contrast, the segment of the population with private insurance or who could pay out of pocket (42%) had a private health care system with access to primary providers, specialists, laboratories, x-rays services, pharmacies and in hospital services at their community level or the nearest municipality to their residency.

Whereas the private sector had 6,000 physicians to attend about 1.9 million persons to access their private services, the Department of Health had less than 1,000 physicians to attend about 1.4 million people. The disparity in the distribution of health professionals was substantial. For this reason the Government was not often ready to deliver services at the preventive level. This preventive intervention should achieve a reduction of the public health system cost at long term.

In pursuing to eliminate or reduce disparities in the accessibility and quality of health services provided to the low-income and uninsured population (+ 60%), an aggressive Health Care Reform (HCR) was launched in PR about two decades ago. The HCR is mandated by Law No. 72 enacted on September 7, 1993 and created the Health Services Administration (ASES, Spanish acronym), responsible for the management of the Government health insurance for the eligible population for this program. The HCR attempts to bridge the gaps in services between the public and private sectors through a GIP. At the same time, one of its goals was to privatize the public health care system through renting or selling its facilities. As a result of the implementation of the HCR, the PRDOH instituted as its top priority the promotion and protection of health.

The GIP has three primary objectives. (1) Privatize the administration of the health service access. (2) Privatize the services lending (3) Implement a managed care to guide the process of privatization and the financing.

ASES is responsible for a number of critical administrative activities, including:

*Negotiating contracts. ASES is responsible for negotiating and awarding contracts to private insurers to provide services included in the ASES standard benefit package on either a fully- or partially-capitated basis through managed care systems.

*Conducting quality assurance. ASES monitors managed care plans by requiring the monthly submission of service utilization data. Reimbursement of the health plans is contingent upon the submission of these reports. In addition, ASES is bolstering its monitoring activities through contracts with a number of organizations; a Peer Review Organization (PRO) is assessing the quality of ambulatory care services, PRDOH is monitoring hospital service quality, and other groups are monitoring regional activities.

*Facilitating enrollment. ASES is responsible for enrolling eligible persons into the new system and coordinates eligibility determination activities with PRDOH. PRDOH Medicaid certification staff stationed at primary care centers determines which clients are eligible for the program and forward this information to ASES. ASES, in turn, provides contracted insurers with the names and addresses of eligible persons so that they can send them letters informing them of their eligibility and inviting them to enroll with a managed care provider in their community. Each enrollee receives a health insurance card which gives him or her access to health care services.

The public health service delivery system was incrementally privatized by July 2000. Under this reformed system, responsibility for providing personal health services to low-

income and uninsured populations holding the GIP was transferred from the PRDOH to the private sector. Currently, all care is delivered through a managed care service delivery model.

After the completion of the implementation of the GIP in July 2000, several laws and changes have been established. These include, but are not restricted to:

*Enactment of Law No. 194, August 2000. This law requires the establishment of an agency to advocate for the rights of patients holding the GIP.

*Enactment of Law 408 of 2000. The PRDOH is retaking the primary responsibility for the provision and coordination of mental health services for the population enrolled in the GIP.

The mental health coverage included through contracted third-party services (Carved-Out) where mental health services are based on a financial arrangement capitation. The benefits included in this cover are:

- 1) Psychiatric Hospitalization
- 2) Partial Hospitalization
- 3) Services for Substance Abuse
- 4) Psychology and psychiatric consults
- 5) Others

*The PRDOH assumed the primary responsibility for immunization services after June 2002.

*Establishment of 14 Clinical Guidelines including Perinatal Services, EPSDT, Guidelines for the management of pediatric patients with asthma and diabetes. In May 2009 current perinatal guidelines was reviewed and expanded to include preventive health measures for women in their reproductive years.

*Increase the length of the contract between ASES and the Health Insurance Company to at least 3 years. In 2008, the major insurance companies that were providing services for the population with the GIP were MCS, Triple C, COSVI, First Medical, MAPFRE and Humana, among others. Each of the 8 Regions is served by an insurance company and by one of the two companies that provide mental health services (Figure II-38).

Because this model has a cost for PR Government (about 14% of the budget), other changes has been under consideration such as contract directly with Health Maintenance Organizations (HMO) providers.

The Department of Health delegated the provision of direct care services to the private sector, through contracts with health insurers, while maintaining the non-delegable core functions of public health. The Department of Health also retained the administration of

certain federal programs and special services such as the WIC program, Medicaid, services for persons with AIDS and the MCH program, among others.

Satisfaction with the GIP

In 2005, the past Governor created a Commission to evaluate the health system of Puerto Rico. This Commission conducted a special study about people's satisfaction with health services. One of the objectives of this study was to identify the differences between private health insurances and the GIP participants in terms of the satisfaction level with the health services. In terms of overall satisfaction with the health services, 90% of the patients with private insurance plans were satisfied compared with 77.6% of patients with GIP. This represents a significant statistical difference ($p < .05$). The analysis by type of health plan satisfaction found that patients with private plans were satisfied with: (1) the quality of treatment, (2) the attention of the medical staff, (3) the explanations of the physician, (4) the sympathy and courtesy of the doctor, (5) the sympathy and courtesy of nurses and other health care professional, and (6) the advice offered by their doctors. In contrast, patients with GIP reported they were satisfied with the friendliness and courtesy of the doctor. Finally, when they compare the satisfaction in all areas assessed, statistically they found that the proportion of patients with health services received with GIP was significantly less than the patients with private plans. The level of satisfaction is the result of several problems that MCH population with government health plan faces.

The assessments of stakeholders consulted in the 2010 HNA identified certain problems affecting MCH population groups that are related to patient-medical doctor relations. Among the problems identified are: lack of explanations on the part of physicians; not answering questions; unwillingness to order tests upon request by patients; women feeling uncomfortable asking questions to physicians; lack of preventive medicine and; ob-gyns control over procedures related to pregnancies and births. In terms of access please refer to page 19 (Satisfaction with the GIP).

Government Insurance Plan Initiative

The health services sector is characterized by the following conditions: various government agencies managing health services, duplication and lack of coordination in the provision of services, lack of integrated data system administration services, multiplicity insurance to demonstrate that the current system known as the HCR is cost effective.

Health care access is one of the Governor's top priorities. By April 2010, the Governor presented the new health plan of the Government, who will experience substantial changes, including change of name to "Integrated Health Model."

The new health model places a greater burden on insurers and seeks to improve access to medical services and extend it to more people. The GIP will include access to specialists without referrals inside the preferred network, will eliminate the primary provider prescription authorization; will integrate mental and physical health in one place; will offer extended time in the medical groups (IPAs); and will require quality measures for the services offered by insurance companies. Also the Governor mentioned that all medical groups should have available the primary services at least until night.

In addition, the Governor is willing to modify the levels income eligibility for those members of the middle class can benefit of the Government health plan. They expect to begin the new changes in September, 2010.

GIP funds

Due to its territorial status, Medicaid funds allotted to PR are significantly lower than for the states; Medicaid funds alone are not enough to provide services for all Medicaid eligible children. To purchase the Government Insurance Plan (GIP) for low income individuals a combination of state, federal (Medicaid and SCHIP) and local (municipal) funds are used. The ASES administrates the funds, whereas the PR Medical Assistance Program is the program that certifies as eligible the low income population (Table II-5) according to the state poverty level (SPL).

In FY 2008, Puerto Rico devoted \$1,483.7 million to finance the GIP for persons with incomes below 200% of the State Poverty Level (SPL). During that same period, PR received in Medicaid funding \$216.1 million, 27% more than FY2007 (\$169.8 million). In FY 2009, these funds had a decrease of 10.9% (\$192.6 million).

SCHIP funds received during FY 2008 experienced a huge increase compared to those allotted during FY 2007 (\$88.1million vs. \$42.5 million). This increment was possible for the unobligated funds of other years, among others. In FY 2009 a total amount of 48 million were used to contribute to buy a GIP. The Medical Assistance Program considers children whose families' incomes are above 100% SPL but below the 200% income level to use primarily the SCHIP funds even though their mothers may not be Medicaid eligible. As the new Federal Health Care Reform, PR expects to receive more Medicaid and SCHIP funds, but it will continue being a capitated managed care model.

Despite increases in Medicaid and SCHIP funds over the time, the quantity of insured population is fewer every year due to the high cost of the GIP premium. According to an analysis of the health system published in 2007, it suggests during the period 1999-2003, the consumption or use of the health services didn't had a growth as high as expected. This implies that the expenditure in the health sector was due to the increase in prices of goods and services consumed.

Organizations providing health services

There are many agencies - not regulated by the PRDOH- that play an important role in some of the phases in the provision of health services since their functions and actions are determinants of the population's health conditions. These represent an important health sector group since most of the services they provide are in the area of health, specifically primary care.

In 2007, a study on Non Profit organizations was commissioned by a group of foundations and other non-profit organization, as part of an effort to present an updated profile of the third sector (Estudios Técnicos, 2007). This study was conducted previously in 1996 and 2002.

According to this study, the hard economic situation and the social deterioration have serious implications for the non-profit organizations (NPOs). These are listed below:

- Their income tends to decrease as a result of the Government fiscal status and by the decline in private donations due to weak performance of the economy.
- The fiscal fragility of the State and the climate in the society increases demand for the NPOs services.
- Emerging new social needs as a result of the economic and social situation.

The situation described above forces the NPOs to put particular emphasis on improving its work with better planning and management. Almost seven of 10 organizations (68.4 %), understand that there will be changes within five years regarding the nature and extent of the services they offer. Similarly, a high proportion believes that these changes will be associated with the increase in demand for services. However, seven of ten entities (65.1 %) expressed that they face problems or limitations in the provision of their services due to economic constraints.

Although in Puerto Rico there is no data to achieve an accurate conclusion, it is reasonable to think that the level of economic inequality has increased, as it has happened in the United States.

In Puerto Rico during 2004 to 2007, the Legislature and the Executive adopted a set of legislative measures to promote the development and strengthening of non-profit organizations. It should be noted that a significant proportion of organizations typically participates as public policy advocates; four out of ten sends communications to legislators; more than a third party participates in views.

Of the NPOs 6,378 identified (Figure II-39), about 58.0 % offer services in municipalities of high density, many of them concentrated in the municipality of San Juan (29.5 %). It's important to mention that this numbers includes NPOs that provide others services such as social, cultural and recreation services, among others. However, although in a different magnitude, the health service areas has occupied the top three positions on all occasions that the study has been carried out (1996, 2002 and 2007). Specifically, the health services and social services were in greater demand, i.e. benefited 264,640 and 249,790 people respectively. About 46% of these organizations provide health related services. Among the health services provided, 30% of the organizations provide prevention services, 24% provide clinical services, and 15% offered medications or mental health services.

A higher proportion of beneficiaries serving by the NPOs that participated in the survey come from the municipalities of San Juan, Bayamón, Ponce, Caguas, Carolina and Mayagüez. Regarding the demographic characteristics, young people, women and children constitute the main populations served by the NPOs. Around five of ten organizations serve at least one of these three segments of the population.

In terms of cost, for each dollar that the Government passed to NPOs to provide health services, the Government should invest \$7 to achieve the same result providing the service directly.

Association of Primary Health Care of Puerto Rico

One of the most important NPOs for the MCH Program is the Association of Primary Health Care of Puerto Rico. The Association of Primary Health Care of Puerto Rico, Inc. (APHCPR) is a non-profit organization that represents corporations, organizations and professionals who provide or have interest in the provision of preventive and primary health services in Puerto Rico that respond to the needs of the communities they serve. Founded in 1984, this entity supports mainly primary health centers in Puerto Rico that receive federal funds from the section of Health Primary USA (BPHC).

For more than 40 years, the APHCPR provides primary and preventive care with a fare cost for the most vulnerable communities in PR. The concept of vulnerable population refers to people - including those with medical coverage - that are excluded from the traditional medical care because of who they are, where they live, the language they speak, and/or the complexity of their medical needs. Moreover, the APHCPR enhances the health care access, irrespective of the pay capacity or medical coverage of the population. They provide services that other health providers do not bring, such as, transportation and medical care. They serve, currently, more than 350,000 patients in 37 municipalities on the Island, approximately 10 % of the total population of Puerto Rico (Figure II-40). The APHCPR and 330 primary health centers are participating in the ABCD Screening Academy pilot project that will promote the medical home model and implement the use of a developmental screening tool (ASQ). The services offered by this network of centers, include:

- Family Medicine
- Generalists
- Internists
- Obstetricians/Gynecologists
- Pediatrics
- Prenatal Care
- Pharmacy
- Clinic Laboratory
- X-ray Laboratory
- Dentists
- Nutritionists
- Health Educators
- Psychologists
- Family planning
- Preventive services
- Vaccination certificates
- Social Work
- Specialized Services

Primary Health Care Facilities

Including the facilities under APHCPR, PR has approximately 138 primary healthcare facilities (Figure II-41). Once again, most of the facilities are concentrated in the metropolitan area; the municipality of San Juan has about 22 primary healthcare facilities. Only four of 78 municipalities do not have a Primary Healthcare facility, 59 percent of the municipalities have one facility and a quarter of the municipalities have 2 centers.

As mentioned earlier, the traditional HCS had primary health care facilities at each one of the municipalities. This was the portal of entry into the HCS for the low-income and uninsured MCH population groups. However, the reality is that primary centers were very under staff. In addition, the majority of the primary providers for women in their reproductive age, infants and children were general physicians who were untrained to address the needs of the high proportion of the at risk MCH population. Besides, they were insufficient in number to serve all the population of the municipality in need of services, including emergency services.

For 2006-2008, there were 66 hospitals in PR. Of this 54 were private facilities, representing about 1.4 hospitals per 100,000 persons. In addition, about 29.1% were concentrated in the Metropolitan Region (to the north of PR).

The major number of beds are found in the general hospitals (10,403 beds in 52 hospitals) representing 255.7 beds per 100,000 habitants. The 7 psychiatric hospitals had about 900 beds (22.9 beds per 100,000 habitants), whereas the two pediatric hospitals had about 356 beds with a rate of 9.1 beds per 100,000 pediatric persons. The two pediatric hospitals are located in the Metropolitan Region. The psychiatric institutions are distributed: 4 in San Juan (Metropolitan Region), 1 in Cidra (Caguas Region), 1 in Ponce (Ponce Region) and 1 in Cabo Rojo (Mayagüez Region).

In an effort to identify accurately where births are taking place in PR, the MCH Program established a Perinatal Care Guidelines Review Committee (PCGRC) during 2007 to classify the hospitals that provide perinatal services. The PCGRC adapted AAP's and ACOG's guidelines to determine which standards could be accomplished by the hospitals. A total of 32 hospitals (response rate 87%) around the Island that served more than 100 deliveries per year participated in the PCGRC initiative. According to PCGRC guidelines, approximately 42% of the hospitals offered only basic perinatal services, whereas 30% offered specialized services and 27% offered sub-specialized services (Figure II-42). Most of the sub-specialized facilities are located in the Metropolitan Health Region, particularly in the municipality of San Juan, but at least every PR Health Regions has one specialized or sub-specialized facility. This is the first initiative of the PRDOH aimed at developing uniform guidelines in order to identify the capacity of perinatal care services of Hospitals Island wide.

Mental Health

In Puerto Rico children and adolescents are MCH groups in dire need of mental health services. These groups include child victims of neglect, abuse and sexual abuse exhibiting problems of learning, experimenting with alcohol and drug with problems of adjustment and behavior.

The MCH Program now has a stronger relationship with the mental health community than in the past. One of the agencies is the Administration of Mental Health and Anti-Addiction Services (ASSMCA, Spanish acronym) that uses the bio-psycho-social approach in the provision of mental health, drugs and alcohol services. Since 1993, the ASSMCA extended their mission as a regulatory agency. They guarantee the access and quality of services for mental health treatment and substance use disorder for the GIP children and adolescents in PR. Among the services they include evaluation and ambulatory treatment, partial hospitalization for children, 24 hours psychiatry emergency rooms for children and adolescents, hospitalization for children and adolescents that have acute psychiatric symptoms, services of residential treatment for adolescents with emotional disorder and substance use. In addition, ASSMCA has the responsibility of evaluate the mental health services offered by other public agencies and promote the interagency and community collaborations for the development of services to attend the needs of children with severe emotional disorder. This program began in 2002 as a result of the organizational structure of the agency based on the manage care model established in 1993.

Despite these services provided by ASSMCA is important to mention that they have very limited resources and the demand for these services is very high. Also, according to the Education and Consulting Coordinator of the Community Health Mental Center in Bayamón there is more than a week of delay for an appointment in various Regions; moreover they have one Region that is providing appointments in 7 months.

Another ASSMCA service is the Mental Health Support Line PAS (Spanish Acronym for First Psychosocial Aid). This toll free hotline reported calls received for information, assistance and help on life situations affecting mental health.

In addition to ASSMCA, two insurance companies cover psychiatric services for persons under GIP. APS Healthcare of Puerto Rico (APSH-PR) is the company contracted by ASES to provide mental health and substance abuse services to GIP subscribers in the East, Metro North, North, Northeast regions and San Juan. They have six (6) Regional Clinics in Arecibo - Manatí, Bayamón - Naranjito, Caguas – Cidra, Carolina – Rio Grande, Humacao – Vieques – Culebra and San Juan municipalities. Only the Regional Clinics in Arecibo (northwest) attend children.

To receive mental health services, the GIP person calls through a toll free number. The Case Manager makes a screening to decide whether the person has an emergency or can receive services through the coordination of an appointment. There are two types of appointments, one through the regional clinics and others with private providers. If she or he decides to go with private providers, APS provides to him or her phone number for the

coordination of the appointment. Once the person has the appointment, she or he has to call again to APS to request an authorization number.

For those who use the services of the regional clinics, APS coordinates the appointment. All regional centers serve children once a week. Arecibo, Bayamón, and San Juan provide services for children every day. This is due to services demand for this population. In the clinics, the initial evaluation is performed by a psychologist and this provider decides if the treatment will be given by a social worker, psychologist, or a psychiatrist.

With regards to hospitalization services for children, there are only two centers located one in Mayagüez and another in Bayamón municipality. The ages of children to receive mental health services under the cover of GIP are from 6 years to 17 years. There are not services for children under 6 years.

The FHC Health Systems of Puerto Rico provides services through the West, Southwest and Southeast Regions. The centers are in Aguadilla, Ponce, Guayama, Coamo, Orocovis and Mayagüez municipalities. The process to receive mental health services is similar to APS services.

One of the challenges that MCH Program, especially the Home Visiting Program, is facing that the mental health services providers do not permit professionals (Visiting Nurses) to make referrals and coordinations on behalf of participants to receive services. It is important to mention that the Home Visiting Program, perform a post partum depression screening to their participants.

Companies aiming to profit have been unable to replace services provided by ASSMCA (during the previous Health Care System) -through the Community Mental Health Centers - and the services to patients have deteriorated greatly.

Health Workforce

For 2007, according to the 10th Registry of Health Professionals, the majority of the health professionals (physicians, nurses, medical technologists and pharmaceuticals) worked in the private sector, contrary to most dentists that worked in the public sector. In particular, PR had about 8,765 physicians, of this, 22% worked in the public sector and 78% of the physicians worked in the private sector.

On the other hand, the majority of the providers that bring health services to the GIP population were in the East, West and San Juan areas. San Juan had the major number of specialist's providers (815 approximately), hospitals (10), pediatric hospitals (2) and psychiatric hospitals (4). There were about 75.8 primary physicians per 100,000 habitants for the GIP population. The total rate of primary physicians was 180.3 per 100,000 habitants.

Four years earlier (2004) there were more physicians providing primary care. The providers available in 2004 were the following: 410 OB/GYN's, 570 pediatricians, 210 family physicians, 410 internists, 1,062 GP's, and 1,289 dentists. However, as of December 2009,

the network of health care providers available to serve the low income population through the GIP was the following: 339 OB/GYN's, 437 pediatricians, 171 family physicians, 189 internists, 1,078 GP's, and 1,342 dentists. Only the General Practitioners and Dentists had a slight increase 1.5% and 4.1% respectively, whereas the other numbers evidence the decrease of primary specialist needed for the MCH Population.

Family Planning

Title X clinics provides comprehensive and accessible services to promote the self-determination of the sexual and reproductive health for men, women and adolescents. Emphasize in the prevention of pregnancies, violence / sexual coercion, drug and alcohol use and sexual transmission infections. There are 28 clinics categorized in: 8 direct referred clinics, 5 in universities, 12 at primary health care facilities and 3 in community, specialized or research programs.

PROFAMILIA offers educational and clinical services in sexual and reproductive health through different educational strategies: education peers, case management, confidential line, group and individual interventions. In 2009, they had two clinics established in the Metropolitan Health Region that comprised of 3 physicians, 3 nurses, 3 pharmacists and 4 pharmacy technicians. Also, PROFAMILIA had two projects that trained adolescents on prevention of pregnancy and other sexual and reproductive health issues and another that was directed to dropout teens and the prevention of HIV/AIDS and STD. Also, they provide contraceptive methods. For the 2009 they reached about 19,964 people through their activities. About 44,060 persons received some contraceptive methods, 79.6% of them used the oral contraception.

Financial barriers to family planning services are significant. Currently, GIP does not cover family planning services, except sterilizations. We fill in the gaps in services needed by WCBA and CSHCN that are not in the GIP package, including contraceptive methods and Rhogam immunization in the 3rd trimester. Despite the actual budget reduction, family planning costs, and legislated salary increase for nurses MCH Program continues providing them. For 2008, over 7,255 women obtain contraceptive methods and 1,385 receive Rhogam per year. This service is provided through the MCH Regions. Women requesting birth control services we are unable to fulfill are being referred to APHCPR, Title X clinics or PROFAMILIA.

On the other hand, one of the challenges that the MCH Program has is the limitation in the number of pharmacies that participate in the distribution of the contraceptive methods. Please refer to Section 3. Strengths and Needs of General MCH populations: Qualitative Data for further details on this issue.

Enabling Services

We know that greater attention should be given to redressing those non financial barriers such as socioeconomic, cultural, etc. and provide enabling or non medical support to the low income MCH Population. As the health reform proposed by the President of the US

continues providing a major Medicaid funds for PR, the medically high-risk population will rise. With this possible expansion, the enabling services become more important.

The Government of Puerto Rico has modified its role of a disease-oriented agency towards one of health promotion, disease prevention and health protection of the population at large. It has also launched several programs to families in need that are managed by different agencies. For example, Department of Family manages programs to provide financial assistance to family groups that do not have the resources to meet their basic needs. This aid is addressing through programs such as Temporary Assistance for Needy Families Program (TANF), Nutritional Assistance Program (NAP), among others. These programs provide services to children and families in general.

During 2005-06, the number of participant families enrolled in the TANF Program increased to an average of 78,245 and a decrease of 81,857 persons was observed. On the other hand, the average number of beneficiaries participating of the Nutritional Assistance Program in 2008 on any given month was 69,106 persons and 53,154 families.

These Programs are experiencing downward trends in the number of families and persons participating. These changes would be the results of the implementation of the PR Welfare Reform Act (PRWORA) and not necessarily it reflects an improvement of the socioeconomic status of the population. On the contrary, we expect that these numbers increase in the future due to the loss of work of many persons.

In addition, due to the financial crisis in the Island, the Government eliminated the Division of the Psychologist Services in the Department of Family. According to the President of the Psychologist Association, the possibility of seeing an increase of domestic violence, violence against children, and criminality are very high.

Other service that is provided for the development of early childhood and their family is through the Head Start and Early Head Start of the Department of Family. It has the major Concessionary of Head Start Program in the Island. Currently, they delegate federal funding of Head Start to 21 delegated agencies. These agencies manage more than 800 centers on the Island, with an enrollment of 18,014 children. All of these services are provided through 10 Regional Offices in Puerto Rico and these offices have at least, one local office in each municipality.

Services thru PRDOH

The Secretariat of Family Health, Integrated Services and Health Promotion (SFHISH) is under the Department of Health and is composed by offices and services that perform strategies and activities geared toward the identification of risk factors contributing to poor health among all individuals. It is also charged with the development and implementation of needed programs aimed at the reduction or elimination of such risk factors and the prevention of diseases. Its approach is based on primary interventions at the community level and with special populations.

Other initiatives or programs have already been implemented by the State to address the health needs of the population at large or to segments of the population with special needs. These initiatives include, but are not restricted to:

Nutritional services

The PRDOH has a special program of supplementary nutrition for women, infants and children (WIC, English acronym). For 2009, this program offered services to 62,874 (19%) pregnant women, 53,209 (16.1%) nursing mothers and postpartum. In addition, they offered a total of 79,234 nutrition services (24%) to infants and 135,000 (40.9%) children. Although not all clinics had nutritionist, certified technical nurse provided nutrition services. The amount of clinics without nutritionist by region was: 166 of (37.5%) clinics in San Juan, 157 (46.7%) clinics in Mayagüez, 14 of (14.3%) clinics in Ponce, 131 of (0.08%) clinics in Arecibo, 133 of (23.1%) clinics in Bayamon and 62 (33.3%) clinics in Fajardo.

On the other hand, during the past three years the MCH Program has been involved in several investigations to evaluate in a comprehensive way the health and wellbeing of the pediatric population, particularly those in the age ranges of 1-14 years of age. We have discovered that only 55% of our second grade students have a healthy weight.

Sexual Assault Victims Center

The Sexual Assault Victims Center (CAVV, Spanish acronym) mission is to provide and coordinate immediate medical and psycho-social services to survivors of sexual assault or domestic violence. Also, this program intercedes to coordinate services of government agencies and community to support survivor's people and educates the community in general and professionals to avoid the revictimization. In addition, they support the prevention of sexual violence (and domestic) using a public health approach of a multidisciplinary team (psychology, education, 24 hours Hot line and inter-agency coordination with hospitals and health centers).

The CAVV has 6 regional offices (Rape Victim Centers) located in San Juan (central), Arecibo, Caguas, Fajardo, Ponce and Mayagüez Municipalities, providing services through the Island. For 2005-2006, those hospitals with emergency rooms reported to the CAVV a total of 1,055 cases of sexual violence. The CAVV reports that the groups most affected by this problem are women and children under the age of 14 years. During this period, of all attended new cases (403) 100% was boys that had 19 years or less, whereas the majority of women (51.2%) were between the ages of 10 to 19 years.

The Immunization Program

The Immunization Program has the responsibility to buy, store and deliver vaccines to all vendors that provide immunization services to the GIP population. This program monitors the managements of vaccines and audits the services offered by providers according to the Pediatric Academy of Immunization (ACIP, English acronym) and the Centers for Disease Control and Prevention (CDC).

The 2009 revised immunization schedule recommends catch up efforts directed to guarantee 11-13 year olds receive a second Varicella dose. It also expands the age range for MCV administration to include children between 11-18 years old, and includes HPV administration for females in the 11-18 age groups. A workgroup has been convened to address the reduction in the number of providers and sites available to immunize privately insured children. Results from the latest study (2007) revealed that the immunization coverage in PR was at least 55%.

Collaborative efforts has been able to establish with public and private entities such as WIC, Private Insurance Companies, providers, schools, pharmacies, grocery stores, and pharmaceutical companies, among others. A key collaborator has been the Maternal and Child Health Division. Our Home Visiting Nurses and Community Health Workers are constantly reminding participants and the community at large of the importance of adequately immunizing their children during home visits, school activities and health fairs.

In order to address the challenges parents of pediatric patients were facing when trying to vaccinate them with the required vaccines several workgroups were convened to analyze the problem and prepare a long term plan that would facilitate and promote immunization within the context of a pediatric preventive office visit. Some of the access barriers they identified were: reductions in the number of special clinics and increased accountability measures put in place to insure compliance with federal funding requirements and the reduction in the number of pediatricians offering immunization services to privately insured children in PR. In order to provide a short term solution to this situation the Governor assigned \$750,000 dollars to the PRDOH in order for it to establish 5 Regional Immunization Clinics. These funds allowed these centers to purchase and administer vaccine to the privately insured pediatric population. Once administered the clinics would bill the private insurance companies and the monies obtained used to purchase additional vaccines. Several private hospitals also followed this lead and opened their own special vaccine clinics within their facilities.

Services through the Catastrophic Illness Program

This program, funded 100% by the State, allows access to very expensive services to individuals with catastrophic conditions. A significant proportion of the patients are children under 21 years of age. They are served either in PR or in the mainland. During FY 2007-08, 105 children benefited from the program with costs ranging from 6 to over 7 million dollars. Its facility is in the Department of Health at central level.

The MCH struggles to enable women, infants, children, adolescents and CSHCN to receive high quality and comprehensive services across a system that is now more complicated. Responding to this need, two (2) new core programs were designed and incrementally implemented across the Island.

Family and Community Health Related Services

Home Visits Program (HVP) is a strategy of prevention and promotion of comprehensive health, focusing on family and community-based. The HVP facilitates and complements

the health services offered at the primary and hospital levels to the maternal and infant population through the Health Care Reform.

The HVP provides case management and coordination services with different public agencies and community organizations through approximately 100 nurses or trained healthcare professionals located in more than 70 of 78 municipalities. Services are offered as from a biopsychosocial approach. The program is intended for pregnant teenagers, women with high-risk pregnancies, families in which there is or suspected abuse, neglect, and abuse of drugs or alcohol, surviving infants from neonatal intensive or with special health needs. As of June 2005, there were 109 HVNs in 74 of the 78 municipalities. The caseload is 45-50 families for a service capacity of nearly 7,000 families per year.

This Program incorporates the Postpartum Depression and Interconceptional Health models. Home Visits Nurses have administered the Edinburgh Postnatal Depression Scale (EPDS) as part of their interventions. This screening tool is composed of 10 statements related with depression symptoms, especially focusing on the post partum period.

Between the long-term results that the Program pursue are listed as follows: reduce preterm pregnancies and the percentage of low birthweight; increase the utilization of primary health in accordance with the periodicity schemes services recommended; increase the use of preventive services such as immunization and medical visits of healthy children; encourage early prenatal care; and reduce the incidence of abuse and neglect of children.

Community Outreach Program

This is another important program developed as a result of the implementation of the HCR. It is staffed by 63 Community Health Workers (CHW) in 63 of the 78 municipalities. Among their main responsibilities are to identify pregnant women and children disconnected from the HCS and facilitate their enrollment into the GIP, coordinate interagency services, give follow up to certain situations of the Home Visiting clients as referred by the HVNs, conduct prenatal courses, provide orientation on MCH topics at the community level, disseminate educational materials, participate in health fairs and data collection, identify problems of access to health services and report to the appropriate level.

Another responsibility of the Community Health Workers is to gather information regarding private and public agencies and services available to the community. They use this information to develop and maintain a comprehensive directory of services which they share with the HVNs. The HVNs use this directory to inform participants regarding the available services and how to access them. This enables the non-HVP population to have the information on how to access the services they need.

Financial constraints and a hiring freeze make replacing HVNs and CHWs difficult. Currently, we have 88 HVN and 63 CHW.

Perinatal Services

The MCH Program has stationed 9 perinatal nurses (PN) at selected institutions that perform a significant number of deliveries. They are also trained in breastfeeding

techniques, family planning, distribution of FP methods and risk assessment of mothers and infants. They provide individual and group education on a variety of topics, make referrals to HVNs and other needed services, collect perinatal data, participate in periodic surveys designed at the central level and are resources for the prenatal courses.

Population-based Services

The MCH Program has directed more efforts to developing new population-based programs and enhancing its involvement with those available prior to the advent of the HCR. These include a newborn metabolic/genetic screening program, immunization program, prenatal care outreach, toll-free information line, public education on MCH topics, dissemination of educational materials, folic acid campaign to reduce birth defects, HIV counseling and testing of prenatal patients, AZT administration to HIV positive patients on a voluntary basis, and Universal Newborn Hearing Screening Program (UNHSP).

Title V funds are used to maintain the NTD prevention campaign, folic acid consumption campaign, injury prevention, and the salaries and local travel expenses of the health educators. These funds are also used to purchase educational materials according to the performance measures and incentives that promote the toll-free line and convey a wide array of health promotion messages.

Comprehensive Adolescent Health Program (SISA, Spanish acronym)

This program integrates all activities directed at reducing adolescent risk factors: pregnancy, unintentional injuries, violence, alcohol and drug use, etc. SISA trains middle school students as peer health promoters and organizes various activities to support them in their work. In collaboration with the Kanopka Institute, SISA is developing a culturally appropriate curriculum on Positive Youth Development and a “train the trainers” guide to promote its application in agencies that serve adolescents.

At the central level SISA is comprised by a multidisciplinary team which includes a physician with training in public health, a nurse, and a social worker. SISA also has 8 Regional Coordinators under the supervision of the Regional MCH Directors.

Early Childhood Comprehensive Program

The Early Childhood Comprehensive Program (ECCSP) is currently pursuing the development of cross-service systems to support children 0-5 years to be healthy and ready to learn. A State Interagency Planning Committee supports the project. ECCSP was transferred to the MCH Program in 2008.

Asthma Program

Addressing asthma from a public health perspective. The CDC supports this project.

Infrastructure Building Services

The PRDOH has been emphasizing in the core functions of public health that include needs assessment, policy development and assurance. This is an area of enormous development after the HCR. The MCH Program established the Evaluation, Monitoring, Research and System Development Section (EMRSDS) to monitor changes in the health status of target populations based on the analysis of qualitative data, surveillance system data, linked data sets, and other MCH relevant surveys.

This Section is staffed by an interdisciplinary team from diverse fields. The team consists of one Demographer, who is the Coordinator Sections and the SSDI Program, two Epidemiologists, one Evaluator, one Biostatistician, and a Cultural Anthropologist. One Epidemiologist is in charge of investigations on reproductive issues and the other on children's health. In addition, the Biostatistician in charge of the PRAMS-like surveillance, whereas the Evaluator in charge of the development and implementation of a maternal deaths surveillance system. The Anthropologist performs the qualitative studies and analysis of the social and cultural factors influencing health. A Pediatrician and an OB/GYN consultant with vast experience in public health provide support the work of this team. The EMRSDS reports to the MCH Director. This team also collaborates with the Title V Director in the needs assessment and monitoring of the Title V action plan, designs instruments to collect quantitative data, and evaluations.

Chronic conditions Services

During the last years, we have been involved in several investigations to evaluate in a comprehensive way the health and wellbeing of the pediatric population, particularly those in the age range of 1-14 years. We have identified some emerging issues that are affecting the pediatric population and require our prompt attention. Among these issues are the obesity epidemic, oral health, unintentional injuries, asthma, autism, violence, hearing impairments and mental health. Many of these areas are already being addressed by the MCH Program with our current programs and activities and reported in the NPM and SPM. Nevertheless, because these are complex issues with multiple associated risk factors, we recognize the need to partner and establish collaborative efforts to address them. Therefore, we will address these conditions by strengthening our PBS and infrastructure building services.

We have discovered that only 55% of our second grade students have a healthy weight. In addition, a study conducted to evaluate the oral health status of third grade students revealed that despite wide dental insurance coverage, services such as dental sealants are being underutilized and there are disparities in oral health associated with type of school. Only 17% of students evaluated had sealants despite the fact 94% of them had dental insurance. Although deaths related to unintentional injuries are not very numerous, they are unacceptable and must be prevented. In addition, PR has the highest asthma prevalence rate in the nation.

Asthma

Asthma is considered one of Puerto Rico's most serious public health problems. PR's asthma morbidity and mortality is the highest among all the US states and territories. Additional studies have reflected that asthma is the second most prevalent health condition in Puerto Rico, and the main cause for hospitalizations when compared with other diseases. Due to this situation, the PRDOH has declared this health condition as a priority of intervention.

According to the 2007 BRFSS, in Puerto Rico approximately 160,000 children under 18 years old (28.4%) were diagnosed with asthma by a health professional at any time in their life. Among them, 13.6 % persisted with asthma. The lifetime and current asthma prevalence seems to be higher in Puerto Rican children than in children in the United States. Childhood asthma seems to be more prevalent in males than in females.

In 2005, PRDOH and the Asthma Coalition impelled the creation of "Law for the Treatment of Students with Asthma". This law, signed on February 1, 2006, recognizes the right of students with asthma or other related conditions to self-administer medications in school with the consent of their parents or guardians.

The MCH Program has a subvention from the Centers for Disease Control and Prevention (CDC) for the development of a capacity to respond to the asthma situation in PR. The main purpose was to develop and establish a Surveillance System and an Asthma Control Strategic Plan in order to reduce asthma morbidity and mortality in PR. This initiative was developed with the collaboration of various agencies and organizations that are members of the PR Asthma Coalition.

The Coalition members include clinical, research, academic, federal and local government agencies, health insurance providers, pharmaceutical companies, among other. It is a leader through its membership in promoting public policy, increasing asthma awareness, and developing strategies to address this serious, costly, and highly prevalent health problem.

During the past years, PRDOH has been implementing efforts for asthma control through collaborations both in and outside of the agency. The Secretary of Health organized an Asthma Committee composed of a group of asthma experts and key people in the health care field who will provide recommendations to develop asthma public policies in PR. DOH also collaborated with the Health insurance Administration in the implementation of changes in public policy to improve the asthma treatment offered by the GIP.

On the other hand, the Asthma Surveillance System has compiled data on utilization of services through three main insurance health companies in PR. The PRDOH and the Asthma Coalition have jointly developed initiatives for asthma control through the improvement of health care provider's and patient's capacity in managing and controlling this disease according to the NAEPP Management guidelines.

In 2008, BRFSS included questions on child and adult asthma. During 2009, the BRFSS is carrying out the Asthma Call-Back which includes an adult and child questionnaire including questions on health care utilization, asthma management, environment,

medications, and cost of asthma care, work-related asthma, co-morbid conditions, and complementary and alternative therapies.

The Asthma Project (AP) and the Puerto Rico Asthma Coalition have identified that one of the most significant barriers towards achieving asthma control of moderate to severe asthmatics is the underutilization of long-acting asthma medications in the management of their condition by the GIP providers. It is believed the elevated costs of these asthma medications is adversely affecting providers' capitation and thus discouraging them from prescribing them according to the established guidelines. Therefore, Administrative Order #248 was signed to improve accessibility to these medications.

The Public Policy Committee continued working to increase the number of GIP asthma patients on long-term medications.

Oral Health Services

Having good oral health is important for the overall health and well-being of children; therefore, monitoring changes pertinent to this measure is a critical function of the MCH Program.

Under the Health Care Reform, oral health services are included in the benefit package. Patients are not required to obtain a referral to get oral health services. They can access oral health whenever they want and with their preferred dentist. The MCH Program conducted a study to assess the oral health status of a representative sample (1,995) of third grade students. This evaluation was done in collaboration with the Department's Oral Health Division and the School of Dentistry of the University of Puerto Rico. Only 17% of students evaluated had sealants despite the fact 94% of them had dental insurance. The study identified two significant barriers to children's good oral health: 1) lack of awareness in the GIP population regarding dental benefits, and 2) the reluctance of general dentists to treat young children.

On the other hand, during CY 2009, there were 1,342 dentists providing services to GIP participants. However, they are not distributed evenly throughout the Island. About 37% were located in the Greater SJ Metropolitan Area and only 14% provide services to Southwest and Southeastern Regions. We calculated that in the Southeastern Region of PR there were 124 eligible GIP children per dentist and that in the Southwest the rate was 117 children per dentist.

Overweight and Obesity

Similarly, the WIC program reported that the most common reasons for a pregnant woman to be enrolled in the program were obesity or underweight, inadequate weight gain during pregnancy, or anemia.

The Alliance for Healthy, Active and Well Nourished Children and Adolescents (AHAWNCA) efforts to conduct the first phase of a study that will allow us to estimate the

prevalence of overweight and obesity in children included in a representative sample of second and fifth grade students attending public and private schools in Puerto Rico. As part of the study, a questionnaire to gather information regarding their eating habits and physical activity level of the child and his/her family was distributed, it also included a question that allowed us determine their health insurance status. According to preliminary data gathered in 1,076 second and fifth grade students, 47.8% held the GIP; 50% ha a private health plan and 2.2% did not have a health insurance plan.

In 2005, a study was conducted to measure the prevalence of overweight and obesity among a representative sample of 3,026 second graders attending public and private schools in PR. This study was conducted by representatives of the MCH Division, Department of Education, WIC, College of Physicians Medical Foundation, AAP, Nutrition Internship Program, School of Public Health and the Private Education Association. The participating students had their BMI calculated and afterwards the students were classified accordingly. Results showed 24% of second grade students had BMI's above the 95%; 16% had levels between 85-94%. Only 2.7% of the students were underweight. No statistical difference was noted by type of school, age or sex. The results showed the PR prevalence rate was higher than that reported by CDC (16%) for children in a similar age group living in the US, but only slightly higher than observed among Hispanic children living in large urban areas in the US.

The Behavioral Risk Factors Survey

This surveillance is a national CDC-sponsored cross-sectional yearly study designed to identify health trends, lifestyles and behaviors among Puerto Ricans. In 2008, BRFSS included questions on child and adult asthma. During 2009, the BRFSS is carrying out the Asthma Call-Back which includes an adult and child questionnaire including questions on health care utilization, asthma management, environment, medications, and cost of asthma care, work-related asthma, co-morbid conditions, and complementary and alternative therapies.

The HIV Prevention Needs Assessment

This study is an Island wide study of a large sample of high-risk populations. The purpose of the study is to identify the health needs of these groups. The results are used to design custom-made HIV/AIDS/STD primary and secondary prevention programs.

MCH Advisory Body (Healthy Start Consortium): It is comprised of about 50 persons representing public agencies, academia, community organizations, and consumers. They provide input on the selection of MCH priority needs and how to address them, help in the coordination of services across public and non-governmental agencies and are resources for professional development.

MCH Regional Boards: These are comprised by members of public and private agencies and consumers. They facilitate coordination of services across agencies and programs and provide recommendations to deal with system problems that interfere with access to services.

Maternal Mortality Review Committee: The committee members include a social worker, midwife, health educator, obstetrician, nurse, pediatrician, epidemiologist and evaluator. It has been meeting regularly to review unidentified causes of maternal deaths with summaries of information gathered on maternal deaths. Based on information gathered and multidisciplinary evaluations, recommendations are made to improve the health care delivery system.

Fetal and Infant Mortality Review:

A FIMR project and a Preconceptive Health Committee are in place.

Other activities include the development of standards of care, interagency coordination, technical assistance and support of community programs, professional development in the area of MCH, information dissemination to concerned stakeholders, policy development and assurance of care, among others.

Coordination efforts with Medicaid Program and ASES

One of the strongest collaborations that MCH Program has is with Medicaid and the Health Insurance Administration (ASES, Spanish acronym). As it was mentioned earlier, PR Department of Health Medicaid certification staff-housed in primary health care centers determine which clients are eligible for the program and forward this information to ASES. ASES is responsible for enrolling eligible persons into the new system and coordinates eligibility determination activities with PR Department of Health. These two agencies, as well as the MCH Program, are under the Department of Health. The changes that are occurring in the Department have resulted in significantly improved coordination with ASES. Through the Home Visiting Program of the MCH Program women are screened and those without insurance are referred to the Medicaid Program. In addition, MCH Program participates in initiatives such as the revision of EPSDT Guidance and the dissemination to the insurance companies through the ASES. This is a strength for the MCH Program to disseminate the mission and other initiatives that we have.

On the other hand, Medicaid Program offers data and information of eligible participants of the GIP. This data is linked annually with live births data. This effort is performed through the SSDI Program.

In addition, ASES as a regulator agency of insurance companies that participates in the GIP collects information about the utilization of the services. The integration of data sets provided by insurance companies poses a challenge for ASES because they have different information systems resulting in fragmented data sets. Therefore, SSDI Program works to ensure the MCH Program has access to accurate, real time data from ASES.

Delegates of ASES participate in MCH Program committees and alliances such as Regional Boards, ECCS Central Regional Committee, Asthma Coalition, Healthy Start Committee, Breastfeeding Committee, Alliance of Healthier Children and Youth, FIMR, among others. This participation is a tremendous contribution because MCH Program

always has the most recent information of GIP services and addresses the more effective way to disseminate information through the providers and insurances under the GIP.

Coordination efforts with WIC

The WIC and MCH Programs are located under the same Secretariat in the Department of Health. This advantage allows develop strategies to provide services for the MCH needed population at state and regional level.

We include WIC staff in different activities such as the development of surveys to perform investigations. PR has experienced an increase in the prevalence of obesity in the population and physicians have noted an increase in DM type 2 in the pediatric population. This situation is an epidemic in Puerto Rico. For that reason, reduction of the overweight and obesity in children and adolescents is one of the priorities for the Department of Health and MCH Program. To address this health problem, MCH Program developed a study for students in elemental grade in order to increase the knowledge of the food habits and physical activities of these students. The collaboration of the WIC Program was very important because they provided us their nutritional expertise and help to design questionnaires to identify risk factors associated with obesity. This staff evaluated the BMI and prepared informational brochure about the healthy way to eat for the study.

A collaborative effort has been ongoing between MCH and WIC. Several weight control programs have been developed locally. The WIC Program replicated the interventions in the Bayamón, Metro and Fajardo Regions used by the MCH pilot project. The project was directed at 3-4 years old WIC participants who had BMIs above the 85th percentile and their parents. The project provided parents five 2-hour didactic sessions on behavior modification techniques and how to improve their child's nutrition. Also, children had the opportunity to exercise during these 2 hours. The Biostatistician, Epidemiologist and Program Evaluator provided the WIC Program TAs to help them design and evaluate a Weight Control Intervention Program. In addition, we share data and trainings.

On the other hand, preconception health is a key factor in the pregnancy outcomes of women of childbearing age. For this reason, the MCH Program set up a Committee for Promotion of Preconception Health with important collaborators, among them, Health Insurance Companies, WIC, Diabetes Program, BD Surveillance System, Academia and Healthy Start Program. A pilot project aimed at post partum women with diabetes was proposed as a strategy to elicit their awareness of the importance of controlling their diabetic condition during the preconception period to improve the results of future pregnancies. The project consists of several educational interventions on diabetes control, nutrition, physical activity and women's health. Two WIC Program clinics in the Western area were chosen as the setting to initiate the project. Special emphasis is placed, first in maintaining adequate health parameters during the preconception period and secondly to initiate PNC immediately if a pregnancy occurs. A full evaluation follows after its conclusion to make modifications if needed and to decide if we expand it to other communities in the island.

Other coordination is through the Home Visiting Program of the MCH Program. CHWs carry out outreach activities to identify pregnant women and children not connected to the health care system and refer them to the HVP or to services available in the community, according to their needs and the capacity of the local HVN to admit new cases. They identified pregnant women and children in the community who were not connected with the existing system of care who were given the necessary referrals to prenatal care, WIC and other services. In 2008, 6,510 families received home visiting services.

In addition, efforts of the MCH Program to decrease VLBW rates are the same aimed at reducing LBW and premature births. These issues are through the HVP providing case management/care coordination, health education and counseling to pregnant women with complex medical and social risk factors associated with LBW and VLBW infants. The prenatal curriculum and the collaboration with others programs such as WIC, are some of the efforts that the MCH Program is conducting to reduce LBW, VLBW and preterm births in Puerto Rico

Efforts of the MCH Program continue through HVP program, Healthy Start and the WIC program with the objective of providing the pregnant women with the necessary tools for a healthy pregnancy and healthy children.

Regards access to information system, SSDI Program coordinates with WIC in order to perform the linkages between the WIC participants and the live births information. One of the challenges that the SSDI Program faces is to have linkages that are more accurate and continuous.

One of the emerging issues and part of the revised priorities for the MCH Program is the consumption of folic acid in the childbearing age. Through the efforts of the Birth Defects Program, WIC Program collaborates to gather data related with consumption of folic acid by the WIC participants locally.

Coordination efforts with AIDS Program

The PR Department of Health has consistently considered a priority the rendering of adequate services to HIV positive pregnant women in the Island. For this reason, a public policy was enacted in 1994 to offer HIV positive pregnant women in the Island the opportunity of treatment with AZT on a voluntary basis to prevent perinatal HIV transmission. Perinatal HIV Treatment and Prevention Guidelines were developed and delivered to health care providers across the Island through the GIP Health Care Insurance Companies offering their services at the time. HCIC required all health providers under their contract to comply with the guidelines. New therapy options were included in these guidelines besides AZT to ensure adequate treatment. Also, the Secretary of Health signed a public policy in February 2008 that requires that all health institutions in PR provide rapid HIV testing in labor rooms for women without evidence of HIV status in the first and third trimester of pregnancy, to treat those with HIV positive results, and to provide rapid HIV testing to those neonates whose mothers could not be screened. The MCH Program collaborated in the process that led to its approval.

Increasing awareness amid pregnant women of the need to know their HIV status and to receive prompt and adequate treatment if the result is positive is essential to reduce perinatal HIV transmission. The MCH Program and the Perinatal HIV/AIDS Prevention Program of the Department of Health (PHAPP) are both engaged in this task. During FY 2008, MCH CHWs reached 529 persons across the Island in 28 educational group events on the subject. In CY 2007, HVN provided one-on-one orientation on HIV/AIDS prevention, including perinatal transmission prevention, to all 6,390 prenatal and interconceptional participants of the program. During CY 2007, the Perinatal HIV/AIDS Prevention Program provided training sessions aimed at health care professionals across the Island, among them those giving services at health institutions, on the importance of preventing HIV/AIDS perinatal transmission, the use of rapid HIV testing, and the adequate follow up and treatment of those pregnant women with positive HIV results. Personnel from agencies and associations related to health care services received educational material on the subject. Likewise, the seven Regional Immunology Clinics have provided their services and knowledge in the prevention and treatment efforts to reduce vertical HIV transmission.

The Perinatal HIV/AIDS Prevention Program, together with the MCH Program and the collaboration of the administrative section of the PR Health Care Reform, will continue monitoring if health care providers are acting in accordance with the perinatal health care guidelines about HIV screening. In this way we will be able to identify barriers and outline strategies to increase the number of pregnant women screened for HIV as well as provide adequate treatment and follow up to those with HIV positive results. We will also continue promoting that pregnant women carry a prenatal card that includes essential personal prenatal care information, including HIV test results.

On the other hand, The HIV Prevention Needs Assessment is an Island wide study of a large sample of high-risk populations. The purpose of the study is to identify the health needs of these groups. The results are used to design custom-made HIV/AIDS/STD primary and secondary prevention programs.

Coordination efforts with Mental Health

During the past years the MCH Program has been gathering data in areas related to children's health. We have identified some emerging issues that are affecting the pediatric population and require our prompt attention. Among these issues is the mental health. One of the key agencies that work with this issue is the Administration of Mental Health and Anti-Addiction Services (MHAASA). In April 2008 a MOU was signed by MCH Program and MHAASA to share direct database from the Monitoring the Future survey (Consulta Juvenil, Spanish name) which measures risk behaviors in adolescents attending schools. This data enables to perform additional in-depth analysis of high risk behaviors among adolescents such as tobacco, alcohol and drug use, and premature sexual activity, among others. Also, the MOU established that ASSMCA collaborates as a consultant in the MCH Program Committees and Alliances and activities; attends those Home Visiting participants and children, adolescents and CSHCN referred to mental services, among others.

The MHAASA Mental Health Support Line PAS (Spanish Acronym for First Psychosocial Aid) crisis toll free hotline reported an increase in the calls received for information, assistance and help on life situations affecting mental health from 34,400 in 2006 to 102,695 in 2007. This increase in the number of calls is related to public awareness due to presentations, media campaigns and distribution of suicide prevention materials in the eight health regions.

The PR Commission for Suicide Prevention (PRCSP) of the Department of Health, composed of representatives of state agencies and non-profit non-government organizations, distributed "Para Salvar Vidas" (To Save Lives) toolkits targeted at the adult and adolescent population. The kit contains information on crisis intervention services, signs and behaviors associated with suicide in adolescents and adults, and ways to handle these situations. Twelve MCH staff - Comprehensive Adolescent Health Services (known as SISA, Spanish acronym) and Healthy Start programs - attended a presentation given by PR Commission for Suicide Prevention (PRCSP) on how to identify signals of suicidal behavior in the adolescent population and general guidelines on how to intervene in these situations. Ten SISA program staff attended a follow-up training to enable them to identify the level of risk for suicide youth are showing and appropriate intervention techniques according to the risk level.

In addition, ECCS Project is currently focusing on the developing and integrating the mental health component in services directed at young children. Also, a working group was convened by the Governor's Office to give recommendations to the Governor on the establishment of a state Advisor Council to address early childhood issues and services. This effort is through the Planning Committee that has multiple collaborators including MHAASA.

Coordination efforts with Comprehensive Adolescent Health Program

This area was under the MCH Program, but we have others collaborations related with this special population. The MCH Program contracted the Naranjito Youth Program, Inc., a community-based organization, to establish a pilot Positive Youth Development project in the municipality of Naranjito to promote healthy lifestyles among youth in community contexts.

The Comprehensive Adolescent Health program (SISA, Spanish acronym) completed, pilot tested and evaluated six training Positive Youth Development (PYD) modules directed at adults working with youth. Eight health professionals from the PR Department of Health attended the pilot trainings. The SISA program revised the "Abracemos La Vida" (Let's Embrace Life) module, which is part of the training program for middle- school students participating in the school-based Youth Health Promoters Project. The module will provide youth health promoters with tools to achieve a healthy life including how to face and manage difficult life situations, anger, anxiety, loss and sadness.

Also they conducted presentations and trainings to disseminate information on and promote the adoption of the Positive Youth Development as an important strategy for the prevention of high-risk behaviors and the promotion of the health -including mental health - of the adolescent population.

Coordination efforts with SSDI Program

There is not a single public or private entity with all the resources and capability to address by itself the multiple and complex socioeconomic and health needs of the MCH population. This team monitors the progress made by all Title V programs towards achieving 18 national, 8 state performances measures, 6 national outcome measures, 9 health system indicators, and 10 health status indicators. Also, is responsible for data collection, analysis and monitoring changes in the health status of our target population. The Section is comprised of public health professionals with different areas of expertise.

The SSDI Program focuses its attention towards insuring Puerto Rico and the Title V Block Grant have access to relevant information and the data necessary for policy and program development as stated in the Title V Health Systems Capacity Indicator #9A. In order to secure access to data that would let us monitor perinatal and women health issues, we have established mechanisms to obtain data from WIC, Medicaid Programs, the Office of Informatics and Advance Technology and Newborn Screening for Hereditary Diseases on a regular basis. By insuring access to these data we are able to perform data linkages and the corresponding analysis that help us inform programs and public decision-makers. The SSDI Program also assists MCH Program in developing evidence-based policies and programs directed at improving the health and well being of the MCH population. This program also has the responsibility of providing external agencies the statistical data and information they need to design and conduct research and establish surveillance activities.

Due to the fact that VS data does not provide all the information needed to evaluate the health and wellbeing of our target population and to measure the progress made towards achieving the PR Healthy People 2010 Objectives, Title V Performance Measures, and HS data requirements, the SSDI Program has been actively involved in developing additional data sources. One such data source is the Maternal and Infant Health Survey (MIHS). This is a customized PRAMS- like survey administered every two years. It allows us to gather information on postpartum women behaviors and practices that can influence their health. Other surveillances and investigations have been developed in order to obtain additional information from the children and adolescents population subgroup. Among them are the Unintentional Injuries Surveillance System, descriptive study of 2 and 5 years old overweight WIC participants, and the qualitative study to evaluate Health and Childhood Obesity from the Adult Perspective: An Ethnographic Approach in the municipality of Gurabo. Title V and SSDI Programs sponsored resources carry out these activities jointly.

The SSDI Program is also taking the lead in performing the ongoing needs assessment evaluation of the MCH population and is in charge of conducting the Title V Five Year Needs Assessment Study due in 2010. Based on the data gathered during this process; Title V was able to review its current MCH priorities and state performance. During this process

SSDI Program was actively involved in gathering input from community level representatives.

MCH Regional Boards

These Boards are multidisciplinary and multisectorial groups of professionals and representatives from different agencies that serve the MCH population. They promote coordinated community-based and family centered services. The SSDI Coordinator, with the help of the MCH Regional Staff, continues reinvigorating the existing SSDI Regional Boards. The MCH Program has 7 MCH Regional Programs that provide community - based services.

The Regional Boards also play a key role in the population based and community – focused needs assessment. This year, the Regional Boards participated in a variety of research activities directed at obtaining qualitative and quantitative data for three specific subgroups: perinatal, children between one to 19 years and children with special health care needs. Our next step is to strengthen the participation of private agencies, and non-profit and profit organizations in the Boards.

Findings of the MCH Program Capacity Analysis

Key MCH Program staff participated in an abbreviated and adapted version of the Capacity Needs tool of the Capacity Assessment for State Title V (CAST-5), second edition. This survey consisted of the revision of several capacity needs listed and the analysis of the extent to which that resource was sufficiently present or in need of enhancement according to the activities and performance goals of the MCH Program. The Key MCH staff checked the box at the end of the survey that indicated whether the program has or needs each resource. For every identified need, they indicated the area of programmatic performance or function for which the capacity was needed.

The Capacity Needs were grouped into four categories of resources:

Structural Resources: Financial, human, and material resources; policies and protocols; and other resources held by or accessible to the MCH program.

Data/Information Systems: Technological resources enabling state information management and data analysis.

Organizational Relationships: Partnerships, communication channels, and other types of interactions and collaborations with public and private entities including, but not restricted to, local, regional, and state agencies; professional associations; academic institutions; research groups; private providers and insurers of health care; community-based organizations; consumer groups; the media; and elected officials.

Competencies/Skills: Knowledge, skills, and abilities of Title V staff and/or other individuals/agencies accessible to the Title V program (i.e., borrowed/purchased staff resources).

Questionnaires were distributed to key staff of MCH Program: Asthma Project Coordinator, ECCS Coordinator, Healthy Start Project Coordinator, Adolescent Health Program Coordinator, MCH Program Coordinator, Birth Defects Project Coordinator, and the MCH Director. About 71% answered the questionnaire.

Overall, the key staff found that the MCH Program should make improvements for each of the four categories. The items that were selected as needing improvement, however, really revealed the development of these resources to a higher level.

For the analysis, we will present those items that 60% or more of the key staff identified as a need. About 19 of 28 items were selected as need.

For the Data/information System Category all the items were selected as needed to be improved. Among the needs mentioned to be enhanced to comply with an adequate capacity are:

- Development of an effective interagency data infrastructure – there are limitations in the technological capacity to support integration of data sets; it is a challenge to access data from external agencies; and there is a limitation of integrated information systems across state agencies or programs.
- Improve access to timely data - specifically with the vital statistics, its very hard to have data in a timely manner from other offices, inclusively, the ones inside of the PRDOH;
- Gathering and accessing data electronically – there are limitations in technological capacity in the MCH Regional Offices, that is, the data collection process and the access to data sets electronically.
- Data collection systems able to feed data back to programs in a timely manner for decision making;

On the other hand, about 71% of the items were selected as need in the Structural Resources Category. The challenges areas to be enhanced are:

- authority and funding sufficient to carrying out advertisings and restrictions to use donations or other funds;
- access to up-to-date information – there is a limitation to access journals and reference resources; there is not feedback for those Law Projects answered by the MCH staff;
- access to online databases for literature searches –although the technology and access to the internet is available, there is a limitation to perform scientific literature searches;
- the community advisory structures and the collaborative planning process between MCH State Office and the MCH Regional Offices;

- the number of adequate staff for carrying out functions in many of the programs inside MCH Program
- a staff member with assigned responsibility for each priority health issue identified in the needs assessment and planning process
- mechanisms or performance standards for accountability and quality improvement for all MCH Program
- regular process for providing information about the effectiveness, accessibility and quality of MCH services;
- the creation of incentives for program improvement

The third Category was Competencies. About 63% of the resources were selected in this category. The needs to be enhanced are:

- communication and data translation skills – this resources could be enhanced with technical assistance in communication - specifically with the communication medias to report objective information;
- technical assistance to develop the ability to influence the policymaking process;
- participation in periodic meetings to be acquainted with what other programs inside the MCH Program are doing;
- the knowledge of environmental health risk in the MCH Population.

On the other hand, about 60% of the items presented in the Organizational Relationships Category were classified as needed in the MCH Program. The following are the needs to overcome:

- State / regional health department/agencies/programs – there are relationships but we should establish them for the benefit to all parties not one way.
- Insurers and insurance oversight stakeholders – we have to work on that every four years when the government administration changes.
- State, regional and local policymakers
- Non-governmental advocates, funders, and resources for state and local public health activities –one of the mayor challenges on which small achievement have been reach while trying to integrate it to the efforts of the MCH Program.
- Businesses – Governmental Ethics Office has been identified as an agency which impedes the collaborative efforts with other agencies. It is considered that this lack may be improved with the assistance of the communication area. It is also mentioned as an important area the business related with employers of women in reproductive age as well as the small businesses.

The qualitative findings about the way Central and Regional Level staff as well as members of the Regional Boards assess the major strengths and challenges PRMCH faces in improving the health and well-being of MCH populations will be presented next.

PRMCH STRENGTHS AND CHALLENGES: A QUALITATIVE ANALYSIS

The Puerto Rico Maternal, Child and Adolescent Division (PRMCH), responsible for administering the Title V Block Grant and other federal grants pertinent to MCH priorities, is divided into two levels: Central and Regional. The Central Level is the administrative, planning and decision-maker responsible for developing programmatic policies, evaluation and research. It is structured into three sections or units. These are: 1) Perinatal, Child and Adolescent Section; 2) Evaluation, Monitoring, Research and System Development Section; 3) Children with Special Health Care Needs Services Section.

The Regional Level operationalizes the work of projects to promote healthy behaviors among targeted MCH populations, that is, program interventions are implemented and executed at the regional level. The Regions as they are commonly called carry out health educational activities targeted both at specific MCH population groups and the general public. They also provide assistance to the EMRSDS section in quantitative gathering and/or coordination with other agencies (for example the Department of Education) to conduct research in specific settings (schools).

As described in Section II (Partnership Building and Collaboration Efforts), PRMCH organized Regional Boards in each Health Region as a collaborative mechanism through which to receive input and establish a work agenda to address the needs of MCH populations. The Regional Boards are composed of representatives from government and non-government agencies that meet regularly (monthly or bi-monthly) to address MCH populations issues. The Regional MCH Directors and designated staff provide leadership to these boards.

As part of the needs assessment, PRMCH staff -from the Regional and Central levels -and members of the Regional Boards were asked to reflect upon the work that is being done to promote the health and well-being of the general MCH populations. In this report discussion will be centered on the strengths, challenges and needs of the Regional Boards, PRMCH and three of its programs. The latter are programs whereby groups of MCH populations (pregnant women, reproductive age women, adolescents) participate on a continuous basis.

Strengths and Challenges of PRMCH

Staff from Central (specifically Perinatal, Child and Adolescent and EMRSDS sections) and Regional levels was probed into the strengths, challenges and needs of PRMCH in promoting the health and well-being of the MCH population groups. In the course of health dialogues, staff described their programs and the work they do and explained them with examples taken from their experiences in health promotion and/or research. Overviews of staff assessments are presented below.

According to some staff the commitment of personnel both in the Central and Regional levels is a major strength of the Division. Commitment in the sense of giving the extra mile when needed, work under duress to accomplish program objectives and using their

own personal resources (cellular telephones, food, incentives in those programs with no funds). As one commented:

“For a number of personnel work is not limited to 8 to 4:30 p.m. schedule. Here we have visiting nurses that obtain donations, food, and other items for the participants of the program. Sometimes they even get them from their own families, perhaps an unused car seat can be taken to a beneficiary. They also work outside official work schedules”.

Most staff members, with few exceptions, mentioned collaborations they have established as key assets. Some paid close attention to collaborations with agencies and programs external to PRMCH. On this one staff said: *“We do a lot of collaborative work. There are also human and funding resources outside the Department of Health through which to enhance the work we do here”.*

Collaborations with outside programs and agencies range from networking to cooperating in certain activities to jointly sponsoring health-related activities. These activities include health education workshops, health fairs, cross-agency professional trainings, participation in committees and/or alliances, information sharing, referrals, and coordination of services and activities. They also include participation in coalitions, alliances, task forces and committees.

Collaboration efforts are strengthened at the Regional Level where programmatic interventions are implemented. Each MCH Region has established relationships with non-governmental and governmental entities in order to reach objectives that cannot be achieved by one single agency or program. Through these relationships Region staff works together with staff from other institutions sharing expertise, skills, and resources to perform health interventions. One Central level staff strongly felt that the Regional Level one of the biggest assets to the Division by saying:

“The Division has personnel in each Region. They connect us to particular situations and conditions in each region. The people [staff] from the regions have a level of integration with other agencies within and outside [Department of Health] much stronger than the staff from the Central Level”.

Some Central Level staff put emphasis on collaborative relationships within the Division underscoring mutual support to carry out tasks related to their respective programs. Mutual support means taking on roles beyond official functions in an effort to complete and/or achieve results. Some even felt people function as family when it comes to helping each other to accomplish tasks to better serve the needs of MCH populations. When asked to explain what it means to be like a family one staff said:

“We are like family here in the Division and regardless of our differences we always work together. My program has no assigned secretary but [names the secretary from another program] supports us 100 percent. We know how to go over the extra mile when someone needs help to complete work, although it may not be related to one’s functions”.

Several staff pointed to the fact that the Division has a well-organized section responsible for the on-going assessment of performance measures and needs through monitoring, evaluation and specific issue research. According to staff, this section provides programs with much needed information or data that allows them to take specific actions. One research staff expressed that the EMRSDS section is “*the eyes*” of the Division providing health information to program coordinators so they can make informed decisions. In this regard, staff within the Section feels that the interdisciplinary team that composes the section is an asset to the Division, “*something which may not even exist in other MCH jurisdictions*”.

Regarding research, there are programs within the Division that have well established surveillance systems to monitor a particular health condition or issue in the MCH populations like the Asthma Surveillance and the Birth Defects Surveillance. The staff of the Birth Defects Surveillance when asked about the strengths of the program had this to say:

“It is one of the most complete programs in the US. Our data is active, they are verified clinically when doubts arise. They are reliable and very accurate. This information is distributed among all professionals they may be interested. I think this program is well positioned in the US” .

In relation to the infrastructure, research staff noted that the established collaborations and systems communications make it feasible to access to information systems and data from a variety of sources. It also facilitates carrying out research in specific sites like for example school settings.

PRMCH also faces challenges to the work performed to improve the health status and well-being of the general MCH populations.

There are communication barriers within programs of the Division that maintains staff separated or unaware of other programs or what a particular program actually does. Some Central Level staff admitted feeling excluded within the Division. As one said:

“We have always been a little bit left behind and for that reason we have made the request to include us in the forums and meetings. For example, an e-mail is sent out about a meeting to be held in the Division but we are not invited. They see us as something apart [separated] and not as integral part of the Division” .

This feeling appears to contradict the idea of family presented earlier. It is important to note that what people refer to is the mutual help that takes place within programs or between programs that share the same physical office space. The physical space becomes a social space whereby workers share experiences, ideas, and knowledge.

Similarly, Regional staff that works with adolescents felt somewhat separated from the rest of the Regional Level. Some feel the youth projects are seen as merely add-on programs

while attention is paid to other activities and programs. To these participants this program should be considered an integral part of Regions.

Central level staff felt that the Division must “*make itself known*” in the general community - professionals within and outside the health field and general public - of the work done to assure improvement of health of important segments of the society’s population. They drew a comparison between the Division and other public agencies. The latter usually announce new initiatives and accomplishments in newspapers, radio and television. The Division should follow suit in letting people know about the programs and services provided.

Acknowledgement of staff work was a stated need that poses a challenge to PRMCH. Up to the present a tendency among directors and administrators has been to focus on limitations of staffs rather than on their strengths and their “sacrifices” in doing their work. According to people’s comments, the focus on limitations has led to “devaluing” the skills and work of staff according to people’s comments. On this issue, a Central Level staff forcefully asserted:

“This is a problem that we have. All the time there are criticisms. You cannot do this or this must be done this other way. Listen, the one that is out there in the street is not me inside here [Central Level]. They [referring to frontline workers] are the ones that pass by streets where drug dealing takes place; they are the one running in and out communities”.

This situation succinctly presented by this staff, may stem in part from the deficit-approach to health that has existed in the Division. Culturally speaking, one can assume that the Division has developed an organizational culture that revolves around deficits and limitations and thus overlooks the strengths of its workforce. Hopefully, the Division has begun moving from the deficit-oriented approach to a strength-health promotion approach. Having adopted the strength health promotion approach may help the Division to face the challenge of recognizing the work of staff and receiving input particularly from front-line workers.

Region staff consulted in the 2010 HNA felt that the Director and other Central Level supervisory staff should listen to the staff from the regions about the programs, needs, concerns and successes. A suggestion was made to have the PRMCH Director visit each Region to listen to the staff. Those that presented this idea firmly believe that listening, stimulating and consulting the staff from the regions will definitively improve their performance and thus the work done to benefit MCH populations. Of course, these staff admitted that some people (referring to staff) may resist all kinds of actions to improve service. Nevertheless, staff must be heard by the Central level administration.

Last but not least, government lay-offs (Law 7) have adverse effects on PRMCH. The Regions have lost MCH Health Promoters (formerly called Community Health Workers), health educators and support staff that limit their capacity to perform needed tasks. Staff is very concerned about the possible mid and long term effects of these lay-offs. Long-time staff has witnessed the negative effects of the 1990’s Health Reform that resulted in having

personnel from public clinics moved to the MCH program. There were people who were assigned tasks for which they were unprepared to perform; today some of these people still have difficulties in the work they do.

PRMCH Programs

Three programs have been selected for in-depth discussion of their strengths and challenges. These are the programs through which we gathered input from the general MCH populations – reproductive age women, pregnant women and adolescents. As mentioned earlier, these programs have groups of MCH populations participating on a continuous basis. The programs are the Home Visiting, Healthy Start, and Youth Health Promoters.

Home Visiting Program Strength and Challenges

This program provides services to pregnant and postpartum women and children up to two years of age with medical and social risk factors. Support to women and their families during their pregnancy and motherhood (first few years) are seen as assets by program staff. One staff referring to Home Visiting Program had this to say:

“The support women receive during pregnancy and the first years of life of their children. They [program beneficiaries] have manifested this in satisfaction questionnaires, in evaluations during participants Committee’s meetings and other activities. They feel they have a family”.

Empowerment of program participants was also seen as a major strength by program staff of these programs. A group of visiting nurses talked about the importance of helping women gain control over health. These nurses view themselves as “*agents of change*” for supporting and encouraging women to lead a healthier life and strongly believe in the importance of empowering program participants. As one commented:

“To empower them through education so they gain knowledge of their rights, the moments they have to have tests performed, educate them about what the physician is doing well and what is doing wrong. To me this is the main function of this program...Empower women and their families”.

Another big strength is the collaboration network established by the Visiting Nurses with other programs, agencies, and physicians to be able to refer and to coordinate services for the clientele.

The gestures and tone of voice of Visiting Nurses involved in a health dialogue expressed pride for the work they do and the concern and love they feel toward participants. They go beyond the program’s requirements in helping women and their families when needed. The commitment is such that they give out their personal telephone numbers and answer calls from beneficiaries at any time (beyond work hours and days).

What do women beneficiaries have to say about this program? Information obtained from several open-ended questions in a satisfaction self-administered questionnaire, women's evaluations of program activities, and testimonies show their views. Altogether this information reveals a possible close relationship between the participant and the nurse that may be critical to open communication channels to address issues related to prenatal care and newborn care. A majority of women participants consistently cited the "*unconditional availability*" and listening capacity of the visiting nurse as an important quality in the intervention process. A sampling of their responses best illustrate their assessments:

"It is her trust, her availability, her understanding to listen to us and help us channel our health problems. Her work goes beyond filling out a document".

"She was always ready to help me at all times; when I needed the most from her, she sought all the available options to help solve my problems".

"She visited me whenever she could even on weekends".

The testimonies of both program participants and the visiting nurses seem to point to the establishment of ties beyond the traditional nurse-patient relationship. For instance, some participants have strongly expressed in various program activities that the visiting nurse is "*like a mother to me*". An implication of this expression is that the visiting nurse may be viewed like a mother (or kinswoman) through her dedication and care for the participants and their families. This may also point to the culture underlying these relationships; personal ties appear to take the form of what anthropologists call fictive kinship that refers to treating an acknowledge non-kinsperson (non-family) as a family member. This will be further researched by the program evaluator and the cultural anthropologist to ascertain the role this relationship has in program effectiveness.

The Home Visit Program is not free from limitations and challenges to address the needs of their participants. One big challenge the program faces is the retirement of visiting nurses and these vacancies are not been replaced. This has left towns (municipalities) in each Health Region without the Home Visiting services.

Another challenge pertains to safety of the visiting nurses as many program participants live in unsafe neighborhoods environments. Fruitless visits are also quite common specially when visiting adolescent beneficiaries.

One limitation of the program is the schedule and possibly lack of coordination of home visits. However, in many cases the visiting nurse lacks the necessary resources such as office telephones to coordinate home visits and services to women beneficiaries. Many program participants have no telephones in their homes or change numbers frequently. Likewise, the Department of Health structure limits the service time frames since public employees must adhere to established work hours from 8:00 am to 4:30 pm.

Healthy Start Program Strengths and Challenges

The Healthy Start program provides support to the Home Visiting program. According to Central Level staff one of the strongest points of the program is the provision of continuous educational and training to staff on emerging issues. Having established the FIMR committee is also seen as an important achievement to work around infant and maternal health. This committee goes beyond statistics to assess and improve services through confidential case reviews.

The Participants' (consumer) Committees are a major asset in the Healthy Start program. The Committees consists of the visiting nurse, women beneficiaries and members of their families (sisters, grandmothers, and mothers) and communities. Women may remain with the Committee upon leaving the program. The Committees were organized to face the problem of non-participation of women in the Healthy Start Consortium (provides input, helps in coordinating services, and serves as pool of resources for professional development).

From women's and staff comments, these committees may possibly represent a social space where women and families not only receive information and training on specific health-related issues but also tools through which to work together as a group. As an illustration, one staff told the story of one local Committee in which the participants took the initiative to face and solve a problem affecting the community where they live. Participants' needed help on what to do to resolve the problem. The Visiting Nurse brought a resource to the group who trained them on writing letters to municipal government officials asking for their intervention. The Visiting Nurse also helped the group on how to approach local government agencies. The group was successful in solving the problem.

The following comments of women participants illustrate the way women assess the benefits of their participation in these committees:

"It has helped me to better communicate with my family".

"It is good because one gets acquainted with others and shares experiences" .

"I greatly enjoy participating because the Committee gives out a lot of information. One doesn't know everything".

"Getting to know new persons from your own community and being able to exchange comments with other mothers".

"It has helped me achieve my goals".

A challenge concerning the Participants' Committees is to train and guide members to new levels of organization and team work to address health and social issues affecting them.

Youth Health Promoters Program Strengths and Challenges

The Youth Health Promoters Program housed in the Comprehensive Adolescent Health Services Program is a school-based project that has been operating since 1992 in public middle-schools in the seven health regions. This program has groups of youth volunteers that undertake health promotion activities targeted at their peers in school settings.

Interestingly, several staff unrelated to the program, mentioned the youth health promoters project as an important asset to PRMCH. The strength of having this program according to these staff lies in having groups of youth targeting their peers to inform and educate them with the aim of promoting healthy life styles. The major strength of this program is precisely having youth volunteers working around health promotion issues of the adolescent population in Puerto Rico. As one staff commented: *“In this group of peers lies the benefit. Sometimes is better to listen to another adolescent the message about what to do and what is done to be healthier than listening to an adult”*.

Youth Health Promoters program staff pointed to the Positive Youth Development as a major strength in working with adolescents. They made a differentiation between their program and other youth programs operating in school settings. As one commented:

“The way we work with youth is that we offer them workshops and information on health. But then, it is up to youth to decide how to give the information to their peers and what kind of strategies they will use. The difference between us and other programs is that they have an established set of tasks and activities that must be done. In contrast, we give workshops and sometimes we bring newspaper clippings on an issue to ask youth how one can handle or work a given situation. And that’s where we depart from other programs”.

Staff strongly felt the program is a multiplying agent in the sense that youth health promoters spread the information out to their peers. Staff also spoke about the effects the program has on the youth health promoters and gave accounts of successes of those that left the program. They also felt that being a sequential and relatively long-term program (youth health promoters remain with the program for 3 years and go through different stages of formation) is an asset.

How do youth participants feel about this program? Information gathered in evaluations, informal conversations with participants, and a health dialogue highlight their views. Youth participating in this program see their role as one geared to help their peers in the school setting lead a healthier life. As they have written in their evaluations of the program, they enjoyed *“helping others”* become aware of the negative effects of certain behaviors. The following is a sampling of their views:

“To help and teach other persons to keep walking the right path in regard to making decisions”.

“Help youth that face any kind of problems”.

“Help other adolescents to make good decisions”.

“Help others to protect themselves from addictions”.

According to these youth, the program has also helped them greatly in staying away from problems and risky behaviors. One theme that emerged relates to the influence of the program on the conduct of youth who had engaged in physical or verbal fights. As some youth health promoters expressed:

“It has helped me to control myself and be more patient”.

“I have more control over my emotions”.

“Little by little I have learned not to be aggressive and to manage my problems and conflicts”.

They also feel great pride in the work they do and expressed a strong sense of belonging that is manifested in comments about the program and the needs they have to better serve their peers. They feel that the program has prepared them *“to speak in public and become health leaders”*.

In a health dialogue youth participants from three different schools explicitly voiced what they see as a major need they have as health promoters. They stated that they are in dire need of having a room or space -in participating schools -of their own to hold meetings and give information and advice to their peers. Echoing others one commented:

“We need a room of ours where we can hold our meetings. And in that room we can also intervene with those persons interested in receiving information about a topic because it is our room and we will have our educational materials in there”.

They strongly felt that having their own place within the school setting will facilitate the work they do, particularly individual help to their peers. As one said:

“If one person has any doubt or problem and wants to consult us, this person will know where to go. That person will say, ‘I know that this is the room [of the Health Promoters] I’m going in there because I know they can help me.’ It is a matter of them not having to search around the school to see who can help them”.

Health promoters went on to explain about the difficulties they often have in holding meetings and keeping program documents and educational materials at hand. As one said:

“Each time we hold a meeting we do so in a different room. Never in a regular room! We never have a place to keep safe things. When we engage in any project, we have to put everything in the [facilitator] office because we don’t have a place where we can put things. What we have is just a borrowed room for the hour of the meeting and nothing else!”.

They also expressed they need a bulletin board to post news, information and other program-related materials. They all agreed that clubs and other school groups do have their own bulletin boards. The words of one youth best express their feelings:

“For example we were doing a collage about teen pregnancy prevention and we were to give information to other students about it. We went to many places in the school but found nothing where we could put up the collage and information. We don’t have a space!”

How big is this challenge to PRMCH? What PRMCH can do to address this need? These are important questions given that there are certain difficulties in the collaborative efforts with the Department of Education.

Another challenge relates to the time school facilitators devote to the program. School facilitators’ work on this project on a volunteer basis and their official duties generally take precedence over facilitating the project. Generally, schools facilitators are teachers, social workers and/or counselors.

A difficulty identified by program staff is that quite often the youth health promoters meetings are cancelled by school officials or facilitators to without prior notification to the MCH Regional Youth Coordinator. Lack of MCH personnel at the regional level to assist in this project is also as a limiting factor in the work done with youth health promoters. All program staff agreed that they need assistance to visit schools, provide training to youth, hold meetings with youth, and maintain contact to follow-up upon the activities organized by youth health promoters. It must be noted that school facilitators are the ones that meet with youth to plan and organize health activities.

In addition, there is the need to have more time for meetings and trainings with health promoters. Each training or meeting session with youth health promoters is given in a time span of 50 minutes. According to staff the real time could be reduced to 40 minutes or less due to the time it takes students to arrive at the meeting room. Quite often the meeting room is not ready or there might be no meeting room assigned yet.

Strengths and Challenges of Regional Boards

Stakeholders involved in the Regional Boards spoke about the strengths of the boards in addressing the needs of the MCH population groups. The strengths identified by regional board members have been grouped according to themes that emerged from their discussions on this subject.

A major strength of the Boards is the collective or collaborative work around health-related issues. Collaborative work takes different forms. One way members collaborate with one another is sharing information about their respective agencies and coordinating activities – such as Health Fairs and others – to inform and educate the general public on health issues.

Another way is to bring resources for training purposes as the Boards serve as a forum to further enhance each individual capacity to work with populations. One member said: *“We have been able to bring external resources. We themselves have been able to bring these persons to offer us conferences like for example childrearing”*.

An important aspect of collaborative work is to discuss emerging issues or needs as well as solving urgent health-related situations of MCH families. On this one commented: *“I see that services the community needs are strengthened. The problem or issue is brought here, we work around it and then offer the service. That help us to speed up due processes.”* Another had this to say: *“One benefit has been to bring specific situations of patients that have been channeled to appropriate services. It has been through this forum [board] that coordination of services has taken place more rapidly”*.

In this regard, stakeholders expressed pride in their ability to help MCH population groups' access services. As one pointed out: *“We have been able to solve all problems. We have coordinated and channeled efforts with pertinent agencies”*.

Members of regional boards often spoke about reciprocity in the work they do. Reciprocal relations have allowed them to coordinate and *“speed up”* processes. Noteworthy these relations take place at meetings but also outside the meetings. As one member explained:

“Because we come from different agencies, private or public, when a situation arises in our community we have our own contacts from within this board. We call each other and ask look I have this situation what can you do to help me? It is something reciprocal. We have brought situations to this board and have sought solutions to them. And when we get here is to inform about what we have done with this family experiencing x situation. This is of great help and is very functional”.

In talking about their strengths some participants made reference to respectful relations established in the Boards. From their comments, members seem to have equal say and to feel very comfortable expressing their views and offering possible solutions to issues raised. One member indicated: *“This very respectful meeting. Everybody listens and contributes and one gets to know many things that benefit all the populations served by each one of us”*.

In most health dialogues with regional boards members it became clear that members highly value commitment to the work done collectively. The term commitment, which to them means *“interest to collaborate to improve the health status”* of populations, was frequently used to describe what some consider a major strength. It also means responsibility to attend meetings and as one said: *“There is a group of committed people who attend regularly and religiously the meetings.”* Very importantly commitment involves motivation to tackle problems as they emerge and to perform needed tasks. As one regional board member expressed: *“Commitment of those here in the Board. One can see a true commitment to work with the population. Commitment is to want to work, to be here and give the extra mile searching for alternatives”*.

Some participants indicated that through the collective work they gained “*consciousness that together they can do more.*” The phrases used by two members of different regional boards best express the feelings (explicit and tacit) of stakeholders:

“We are the spokespersons and defenders; always vigilant that we give the best of us to guide and empower families.”

“One becomes conscious that we really are an important tool for this society.”

The Regional Boards face a number of challenges that at times make it difficult to perform their work and achieve results.

A challenge faced by the regional boards relates to incorporating additional agencies into their membership. For instance, some members report the difficulties they have had in integrating the Department of Education into their work. Participants pointed to the unresponsiveness of the bureaucracy within the Department of Education to invitations to join the Boards. One member commented: *“Bureaucracy in the Department of Education. We have done all moves but they do not respond. We understand that this department should be represented here, after all we all work with their population.”*

The recruitment of community-based organizations and families is another challenge that at least one regional board has attempted to no avail. On this issue a member commented: *“In my understanding one of the challenges, as well as a difficulty, is to recruit community members. For example, we have had persons from the community, persons who have come and have committed themselves to keep coming but then they do not show up anymore. A young woman came, a grandfather representing the community came but we have been unable to retain them.”*

Continuity of agency representation is a serious limitation and challenge. Members often talked about having the same people attend meetings due to participants’ turnover. *“What is happening is that you come every month and you see the same faces. We are the same committed people. You call the Justice Department and they may send a lawyer, but he/she may excuse himself or herself from the next meeting. Then they send another representative that has to be explained all over again what is the Board.”*

One challenge representatives from each participating agency face is influencing top level administrators regarding procedures and programmatic interventions with families and communities. To some members top level administrators impose programmatic policies to middle and lower level public officials that quite often have no connection to what is taking place in social and geographic contexts. A board member said: *“A big challenge would be to change the way of thinking of those persons occupying high level positions so they could understand the need for services in this society.”*

Given the knowledge and front-line work most members perform, proposing public policy was seen as an activity that should be undertaken. Indeed, in several health dialogues members explicitly expressed interest in taking actions to influence public policy. As one said:

“Propose public policy in a given time. From what we have been talking about, administrators at top levels of government are unaware of many things. You see, we should suggest public policy in order to mend certain errors”

A challenge presented in one health dialogue is to have more support from PRMCH Central Level. One member stated that in past years, there existed a *“Central Level Board composed of delegates from the different regional boards to discuss issues.”* A related issue is the need they have in organizing inter-regional boards meetings to have the opportunity to share experiences and advance a health agenda.

Most members involved in health dialogues emphasized the need to reach out to the general public through the use of means of communications like newspapers, radio, and television. As one commented:

“It is through the mass media like radio, press, television that one can reach many people. Quite often people are invited for a meeting but they don’t show up. There are local newspapers, radio stations and radio programs that provide public service [free of charge]. There should be state massive television campaigns to reach out to those in most need of services”.

Some challenges relate to the transformations underway in the different agencies in the PR government. As was discussed previously, there have been massive lay-offs of workers and professionals from the public sector. Lay-offs hinder the ability of public officials to assist to meetings and continue involved in different committees. One said: *“We have fewer personnel and we have to work more situations and that makes even more difficult to attend meetings”*

Stakeholder members repeatedly and consistently spoke about the negative effects changes introduced by Law 7 in public agencies. Members pointed out that Law 7 has negatively affected services provided by public agencies, increasing workers’ responsibilities and the tasks they perform, thus reducing their capacity to effectively serve the needs of populations. Uncertainty about the future was repeatedly expressed by members of Boards. The words of a stakeholder best expresses the uncertainty public officials feel: *“One has to ask, are we the existing agencies will be here ten years from now?”*

Concluding Remarks

There are several points that ought to be underscored regarding the strengths and challenges of the Maternal, Child and Adolescent Health Division, and thus, PRMCH.

First, the Division has a structure composed of two levels – Central and Regional; various committees addressing health issues; a whole section devoted to health research; a variety of programs geared to improve the health status of MCH populations; a regional board in each PRDOH health region and; three programs where MCH populations participate on an on-going basis. From a holistic perspective and considering the MCH core functions all

these segments intertwined; Title V being the inner core from where all programmatic policies and actions emerge.

Staff comments are suggestive that in practice not all parts fit together and much more work needs to be done to remedy this situation. In this respect, PRMCH faces an important challenge – integrating individuals (staff) and programs into an effective whole with shared organizational meanings and values stemming from core MCH functions and needs of the populations served.

Second, staff and members of boards expressed overt and implicit values and norms (expectations) that highlight –albeit limited- the cultural meanings and practices in the workplace and/or the social space where people work together towards common goals. Some of these values and norms are:

- Genuine concern for the well-being of populations served in their respective programs or projects.
- Empowerment of populations so they can gain more control over their health and lives.
- Proudful teamwork based on mutual respect and professional pride.
- Less or non-competitive work
- Generosity in helping others and going beyond their official tasks or duties.

In terms of day to day interactions, the cultural anthropologist has observed that the secretarial and support staff works closely with programmatic and research staff to complete tasks. It is quite common to see two or more staff either from the same program and/or section or from different programs having informal meetings to discuss issues related to the work done for MCH populations.

Third, the Youth Health Promoters program deserves closer attention because it is composed of groups of adolescent volunteers that take on the task of promoting healthy life styles among their peers. These youth show a strong sense of belonging in being a health promoter and great pride in helping others to such a degree that they seek to improve the work they do. Unfortunately, as the cultural anthropologist has observed, this program has been largely overlooked as an important part of PRMCH. It was and still is the forgotten and invisible program and few people acknowledge its significance.

Fourth, PRMCH faces the challenge to address health disparities. As it can be remembered from the qualitative analysis, some of the needs of the general MCH population groups are directly related to disparities in access to health care (scarcity of providers, structural barriers like transportation, excessive time spent in waiting for service, etc.) and quality of health care (for example, patient-provider communication and lack of preventive care). Although PRMCH has had successes in influencing public policy to reduce disparities much more work still remains to be done in this area.

Last, the greatest challenge for PRMCH is to develop an organizational culture (within a bureaucratic system) that supports the integration and engagement of staff - other than program coordinators - in programmatic decision making and on-going needs assessment. It is to be noted that this was the first time that the staff was consulted and viewed as stakeholders. Indeed, the staff was thankful for having the opportunity to give their views and voice their concerns. The same challenge applies to continuously engage the regional boards, committees and program participants in program development and needs assessment. In addition, to bring community-based (grass-roots) organizations and general MCH population families into the Regional Boards needs to be addressed in order to integrate them into the work of PRMCH. To face this challenge will mean to enhance MCH functions at each level of the pyramid.

5. PR MCH SELECTION OF PRIORITY NEEDS

a. Methodologies for Ranking/Selecting Priorities

The process for the selection of priority needs began with discussions about the findings, objectives and the procedures to be used to select priorities. As part of this process, we translated and adapted the Needs Prioritization Method Tool used by Louisiana State in 2005. Face validity was performed to review the instrument's items. The adapted instrument consists of three parts: 1) priority selection; 2) Ranking top 20 priorities with the highest scores; 3) strategies or actions for each priority selected. X

We identified 42 potential needs priorities (Table II-2) after an analysis based on findings of the Health Indicators Questionnaire, Health Dialogues and the Key Informant Interviews. Other health needs were included such as unintentional injuries, gastroenteritis and otitis media for children 1 to 14 years according to the information provided by pediatricians that participated in the PR Annual Meeting of the American Academy of Pediatrician Puerto Rico Chapter. The qualitative analyses (mainly from the health dialogues and key informant interviews) provided other needs and confirmed the majority of the health needs identified through the Health Indicators Questionnaire. Also information based on the PM, SPM, OM, HP 2010, input from collaborators, state political priorities, and accessibility of resources to address documented needs was analyzed. To narrow potential priorities, PRMCH convened a two-day stakeholder meeting that included representatives from public agencies within and outside the Department of Health and private organizations. Stakeholders invited were: Regional Boards Presidents, MCH Projects Coordinators, Folic Acid Program, ASSMCA, ASES, Booz Allen Hamilton Inc., Health Insurance Commissioner Office, Department of Family, United Funds, American Academy of Pediatrics, WIC Program, Adolescent Program of Naranjito Inc. and two community participants of Healthy Start. A total of 19 participants from the following agencies assisted to the two-day stakeholder meeting: ASES, Adolescent Program of Naranjito Inc., PRMCH, Regional Bords Presidents, Booz Allen Hamilton Inc., WIC Program, Department of Family, MCH Projects Coordinators (SSDI, Folic Acid Program, Integrated Adolescent Health Services (SISA, Spanish acronym) and ASSMCA.

The first and second parts of the instrument - containing the 42 potential priorities - were distributed among stakeholders prior to the meeting. Stakeholders were instructed to select 20 potential priorities from the list based on the following criteria: the extent/magnitude of the health problem, severity of the consequences, resources availability, and level of public acceptability. Quantitative and qualitative information of health status indicators were also provided to stakeholders as part of the priority selection process.

At the consensus meeting EMRSDS staff gave two presentations: 1) the process used to select potential priorities and; 2) a description of the status of each one of the identified 42 needs contained in the instrument. Once the presentations were over, time was given to participants to individually review their selection. After this review, the answers were handed in to staff to sum up the scores. Fifteen (15) potential priorities (Table II-2) out of forty two (42) were selected considering their higher scores and that they were not included in any PM, SPM, OM, HSCI or HSI.

A second round of selection took place using a table of strategies and activities for each one of the fifteen (15) potential priorities. The strategies and activities were classified as short (1 year) or long (5 years) term. Also effectiveness and availability of resources for each activity was assessed. Effectiveness was classified as high (3 points), moderate (2 points) or low (1 point); whereas the availability of resources for each activity was classified as not available (1 point), moderately available (2 points) or totally available (3 points). If the strategy scored 4 or more, it was considered as a good strategy. The stakeholders identified at least 3 strategies for each potential priority.

Upon completion of pre-selecting priorities, a General MCH Population Workgroup was organized to discuss the potential priorities identified by the stakeholders in the two-day meeting. The Workgroup consisted of the MCH Director, Programmatic Coordinator and the EMRSDS team. This Workgroup held several meetings to discuss the allocation of resources, data sources availability and type of interventions. The fifteen (15) potential priorities were then categorized in seven (7) main priorities for the general MCH population. The CSHCN Section performed the selection of priorities for the children with special needs population. They identified three (3) priorities for the CSHCN. As a result the work plan of the MCH Program focuses on the following priorities:

1. Improve WRA health at the time of conception.
2. Develop continuous and reliable data sources and surveillance systems.
3. Decrease premature births.
4. Decrease morbidity due to chronic conditions in the pediatric population.
5. Reduce unintentional injuries among children and adolescents.
6. Strengthen the socio-emotional development in the pediatric population.
7. Promote healthy life style in adolescents.
8. Increase the number of empowered CSHCN families by promoting family competency to identify and manage their child needs through family centered-care.
9. Increase the number of CSHCN that receive coordinated care services.
10. Increase the number of YSCHN that are well oriented for their transition to adult life.

b. Priorities Compared with Prior Needs Assessment and MCH Capacity:

As mentioned earlier, the selection of priorities was through a designed instrument that was given to different stakeholders and staff members from the MCH Program. According to the stated criteria in the instrument each potential priority was scored. Fifteen (15) out of forty two (42) priorities were selected and were categorized in seven (7) main priorities for the MCH population and three (3) priorities for the CSHCN. Following is a brief discussion for why each priority continued, replaced other priority or was added for this next year's work plan.

1. Improve WRA health at the time of conception.

This priority replaces priority No. 1 from 2005. It not only considers mothers but also WRA that are potential mothers. Preconception care, STD's, use of folic acid,

birth defects and domestic violence are amongst the issues discussed in the priority selection and that affects WRA. MCH capacity: Strong relationships with Association of Primary Health Care of PR to make referrals; Home Visiting Program assessments of participants' health and risk factors; Identification of women who may need services by Community Health Workers; Folic Acid Annual Campaign; referrals to Family Planning services and distribution of contraceptives methods in participating pharmacies; Birth defects surveillance; referrals to WIC; Maternal Mortality Surveillance System.

2. *Develop continuous and reliable data sources and surveillance systems.*

The MCH Program runs several studies and Surveillance Systems that are useful sources of information to monitor the MCH population. However, some of them are not representative of the entire population or lack information that would be useful for other areas of the MCH population where other sources are not easily available. Therefore, because of the need of continuous and reliable data sources and surveillance systems, this priority was added in 2010. MCH capacity: Collaborations with Medicaid, ASES, WIC, newborn screening to access data; MCH surveillance active surveillance systems (maternal mortality, asthma, ESMR, FIMR, birth defects).

3. *Decrease premature births.*

The percent of premature birth in PR is 20% and we are in first place compared with other states and properties of US. Since premature and low birth weight infants are the first cause of infant mortality in PR, this priority was added in 2010. Decreasing premature births will definitely help decrease infant mortality in PR. MCH capacity: collaborations (March of Dimes, Primary Health Centers); referrals to Family Planning services and distribution of contraceptives methods in participating pharmacies; FIMR; Surveillance systems.

4. *Decrease morbidity due to chronic conditions in the pediatric population.*

This priority replaces priorities No. 3 and No. 8 of 2005. By decreasing morbidity due to chronic conditions in the pediatric population, issues like immunizations, asthma and obesity are considered. MCH capacity: Participation of MCH staff in the Alliance to prevent children's obesity; Participation in Asthma Coalition; Prevalence studies; Oral health status study of third grade students; Collaborations with GIP, WIC and Head Start.

5. *Reduce unintentional injuries among children and adolescents.*

This priority continues (No. 6 in 2005) since unintentional injuries are the first cause of death in the pediatric population. Furthermore, long term consequences of unintentional injuries in children and adolescent must be considered as a problem in this population. MCH capacity: Access data related to injuries from different sources.

6. *Strengthen the socio-emotional development in the pediatric population.*
Abuse and neglect in children, mental health problems and other behavioral problems in children are emerging issues in this population. Therefore, this priority was added to the 2010 work plan. MCH capacity: Collaborations with ASSMCA, Head Start; Home Visiting assessments and education; Early Childhood Comprehensive System.
7. *Promote healthy life styles in adolescents.*
This priority replaces priorities No. 4 and No. 5 from 2005. Promoting a healthy life style in adolescents includes reducing behavioral risk factors like use tobacco, alcohol and drugs, use anti-conceptive methods, interpersonal violence, suicides, and teen pregnancies. MCH capacity: Youth Health Promoters; Collaboration with Naranjito Youth Program, Department of Education, Family Planning Services; Education and information to youth by Community Health Workers; Comprehensive Adolescent Health Services
8. *Increase the number of empowered CSHCN families by promoting family competency to identify and manage their child needs through family-centered-care.*
This is a new priority. In each of the health conversations and almost all YSCHN interviews the importance of empowered and informed families was brought up. Stakeholders also ranked it as the second most important issue to address. This priority is related to direct health care services and infrastructure-building services.
9. *Increase number of CSHCN that receive coordinated care services.*
This priority continues from the previous needs assessment "Improve coordination among health care plans, primary physicians and the Pediatric Centers." Care coordination is one component of the medical home. This priority is related to direct health care services and infrastructure-building services of the pyramid. The 2010 needs assessment revealed that care coordination is our weakest medical home component.
10. *Increase the number of YSHCN that are well oriented for their transition to adult life.*
This priority continues from the previous needs assessment. Transition services are enabling services. PRS-CSHCN data shows that only 26% of youth with special health care needs receive the necessary services.

c. *Priority Needs and State Performance Measures:*

Following is a description of how PR will measure success in meeting each priority need, including how it has linked the Priority Needs with the States Performance Measures (SPM).

1. *Improve WRA health at the time of conception.*
WRA with STD's, unplanned pregnancies, birth defects and folic acid consumption, were among the selected priorities that could help measure the state of health in WRA at the time of conception.

A new SPM (No. 1) was chosen for this priority, the proportion of women of childbearing age consuming folic acid. Folic acid is an important nutrient for women who may become pregnant. Serious birth defects like neural tube defects are less likely to occur when women take 400 mcg of folic acid daily, before pregnancy.

SPM No. 2 where the prevalence of neural tube defect (NTD) was measure will continue as part of this year's Needs Assessment as well. This will allow measuring the folic acid intake and seeing how this reflects in NTDs.

The Health Status Indicator (HSI) 5A and 5B measures the rate per 1,000 women aged 15 to 19 years or 20 to 44 years with a reported case of Chlamydia, which is the most prevalent STD. In addition, the STD's Surveillance System of the PRDOH works directly with this issue. Therefore, the PR MCH Program will follow STD's thru this HSI and with the help of the STD's Surveillance System.

Unplanned pregnancies are not measured in any way by a Performance Measure (PM), and although there is a reliable source of information for this data, the MCH Program recognizes the lack of capability at working with this issue. Nevertheless the MCH Program will closely monitor unplanned pregnancies and will continue educating women on the importance of family planning.

2. *Develop continuous and reliable data sources and surveillance systems.*

Data sources that are continuous and reliable are important for an accurate measurement of the PR MCH needs. That is why a new SPM (No. 3) was developed in order to assure continuous availability of quality data reports regarding the maternal, adolescent and child population in PR. Seven characteristics documenting data collection, analysis and dissemination for the ongoing needs assessment will be evaluated:

1. At least one functional Birth Defects Surveillance and Prevention System will be operating, and key findings needed for public health planning and for engaging the public in preventive measures will be reported to Puerto Rico Department of Health (PRDOH), the State Government, and the public.
2. Biennially salient findings from the Maternal and Infant Health Survey (ESMIPR) will be reported to Puerto Rico Department of Health (PRDOH), the State Government, and the public. The Maternal and Infant Health Survey (ESMIPR) is administered to a random sample of postpartum women in all hospitals with 100 births.
3. At least one functional Epidemiologic Maternal Mortality Surveillance System (SiVEMMa) will be operating, and key findings needed for public health planning and for engaging the public in preventive measures will be reported to PRDOH, the State Government, and the public.

4. At least one functional Fetal and Infant Mortality Review (FIMR) will be operating, and key findings needed for public health planning and for engaging the public in preventive measures will be reported to PRDOH, the State Government, and the public.
5. Biennially salient findings from the Maternal and Child Health Research key findings needed for public health planning and for engaging the public in preventive measures will be reported to Puerto Rico Department of Health (PRDOH), the State Government, and the public.
6. Annually salient findings from the Integrated Index of Maternal and Child Health by Municipality (IISMCH) will be reported to PRDOH, the State Government, and the public.
7. The PR Child with Special Health Care Needs Survey is being conducted at least every five years.

These characteristics will be evaluated in terms of: not met or no progress (0), partially met or some progress (1), mostly met or great deal of progress (2) or completely met or completely done (3). This will allow us to determine if the data sources of the MCH Program are indeed continuous and reliable (Table II-7).

3. *Decrease premature births.*

Since premature births and low birth weight babies are the first cause of infant mortality a new SPM (No. 4) will measure this priority.

Late preterm babies account for 75% of preterm births in PR. Late preterm babies often weigh between 4.5 and 6 pounds, and they may appear thinner than full-term babies. These babies remain at higher risk than full-term babies for newborn health problems, including breathing and feeding problems, difficulties regulating body temperature, and jaundice. Because their brain development is not complete, these babies may be at increased risk for learning and behavioral problems.

By decreasing late preterm babies the MCH Programs expects to decrease premature births in PR and consequently infant mortality rates.

4. *Decrease morbidity due to chronic conditions in the pediatric population.*

Issues such as dental cavities, overweight/obese children and asthma were considered under this priority. PM 9 measures the percent of third grade children who have received protective sealants on at least one permanent molar tooth and PM 14 measures the percentage of children ages 2 to 5 years receiving WIC services with a Body Mass Index at or above the 85th percentile. Although there is no PM aimed at asthma, there is a Health System Capacity Indicator (HSCI) that

measures the rate of children hospitalizes for asthma. In addition, the MCH Program counts with the Asthma Surveillance System and the Asthma Project that closely monitors the incidence and prevalence of this condition.

Hence, there is no new SPM to measure the decrease due to chronic conditions in the pediatric population, for we expect to measure this priority need successfully thru the already stated PMs and HSCI.

5. *Reduce unintentional injuries among children and adolescents.*

Unintentional injuries represent a serious problem of public health in Puerto Rico. These are the first cause of death among the pediatric population aged 1 to 14 years. The problem of unintentional injuries is not only the deaths but the numbers of survivors that are affected through the rest of their lives. A formula has been identified to estimate the magnitude of the unintentional injuries. This formula indicates that for every death due to unintentional injury occurs: 40 hospitalizations, 1,120 emergency room visits and 1,600 physician's office's visits.

There are PMs and HSIs that will help the MCH Program measure the success in meeting this priority. PM 10 measures the rate of deaths to children aged 14 years and younger caused by motor vehicle crashes, whereas HSI 3 (A, B and C) measures the death rate due to unintentional injuries (total and motor vehicle crashes) in children 14 years and younger and youth 15 to 24 years old and HSI 4 (A, B and C) measures the rate of all non-fatal injuries (total and motor vehicle crashes) among children 14 years and younger and youth 15 to 24 years old.

In addition, a new SPM (No. 5) will measure the rate of children aged 1 to 14 years that visit the emergency room due to all unintentional injuries. Through various activities the MCH Program expects to reduce the number of emergency room visits among children aged 1 to 14 due to all unintentional injuries.

6. *Strengthen the socio-emotional development in the pediatric population.*
Child abuse and neglect was the issue with the highest score in the Needs Assessment. Mental health in the pediatric population was other concern, especially because this is scarcely addressed.

A new SPM (No. 6) will measure the number of pre-scholars who present behavioral problems. Monitoring psycho-social health status of pre-school population could lead to the development of early interventions necessary to improve their learning capacities. Pre-school children have increasing needs for mental health services (such as ADD, learning problems, autism, mental retardation, among other disabilities), especially those exposed to neglect, and physical and sexual abuse. Early intervention is necessary to address learning disadvantage, difficulty to adjust to school or to society, and early risk behavior.

7. *Promote healthy life styles in adolescents.*

Drug, alcohol and tobacco use, sexual activity, suicide and interpersonal violence were among the issues that were constantly mentioned during the Needs Assessment.

The Positive Youth Development Model (PYDM) looks toward creating supportive communities for all young people and at the same time, engaging youth to contribute to the well-being of the larger community. Organizations and communities that promote PYDM give youth the chance to get involved and exercise leadership.

A new SPM (No. 7) will measure the degree to which selected organizations incorporate the PYDM in the services provided to adolescent. Eight characteristics documenting the PYDM implementation in organizations working with young people will be measured. These are:

1. Staff provided with training opportunities on youth development concepts and strategies.
2. Organizations encourage partnerships and collaborations with other agencies and organizations in order to provide more opportunities and supports for young people.
3. Programs are culturally sensitive; they recognize cultural strengths and differences, and meet the needs of diverse population.
4. Young people are viewed as resources and are actively engaged in planning, implementing and evaluation programming.
5. There is designated staff to support youth participation (to ensure recruiting, preparing and sustaining young people to be actively involved in the organization).
6. The organization's mission reflects youth development principles.
7. Organization shifts from preventing problems to creating positive outcomes (such as competencies, connections and caring relationships, positive values and expectations, meaningful participation).
8. The organization reached maximum youth participatory level.

These characteristics will be evaluated in terms of not met or no progress (0), partially met or some progress (1), mostly met or great deal of progress (2) and

completely met or completely done (3). This will allow us to determine if the PYDM is well implemented in organizations that serve the young population.

Another new SPM (No. 8) will measure the percent of youth 10 to 19 years old who adopt specific healthy life styles such as physical fitness, healthy food, safe sexual practices, and smoking, alcohol, and drugs cessation, while served by selected organizations working with the PYDM. The Puerto Rico Youth Development Survey will be designed to understand how long youth reached by the selected organizations working the PYDM, change to healthier life styles, are more empowered, experiment better social inclusion, and has more participation.

8. *Increase the number of empowered CSHCN families by promoting family competency to identify and manage their child needs through family-centered-care.*
This is a new priority. In each of the health conversations and almost all YSHCN interviews the importance of empowered and informed families was brought up. Stakeholders also ranked it as the second most important issue to address. This priority is related to direct health care services and infrastructure-building services. Outcome will be measured by National Performance Measure # 3: The percentage of CSHCN that receive comprehensive, coordinated, and family-oriented centered services through medical homes.
9. *Increase number of CSHCN that receive coordinated care services.*
This priority continues from the previous needs assessment “Improve coordination among health care plans, primary physicians and the Pediatric Centers.” Care coordination is one component of the medical home. This priority is related to direct health care services and infrastructure-building services of the pyramid. The 2010 needs assessment revealed that care coordination is our weakest medical home component. Outcome will be measured by National Performance Measure # 3: The percentage of CSHCN that receive comprehensive, coordinated, and family-centered services through medical homes.
10. *Increase the number of YSHCN that are well oriented for their transition to adult life.*
This priority continues from the previous needs assessment. Transition services are enabling services. PRS-CSHCN data shows that only 26% of youth with special health care needs receive the necessary services. Outcome will be measured by National Performance Measure #6: The percentage of YSHCN who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

6. OUTCOME MEASURES

The health status of the maternal, child and adolescent population in Puerto Rico has improved to some extent when observing several maternal and child health outcomes throughout the last decade. Nevertheless, there is still a considerable disparity among neonatal, postneonatal, infant perinatal and maternal mortality rates when compared to national established targets for 2010. A large number of babies are dying before delivery, in the neonatal period and the post neonatal period. Likewise, an unacceptable number of mothers die every year, particularly due to preventable conditions, leaving their children orphans. The contributing factors are numerous. Consequently, partnership of all sectors of the society is decisively needed to reduce the gap between the current situation and the set goals. There is also an urgent need to fix the health care delivery system in Puerto Rico.

Title V's main goal, improving the health and well-being of all women in their reproductive age, infants, children, adolescents and their families, must be the desired end result of the collective accomplishments of the National and State Performance Measures.

To achieve this, the PRMCH engages in a varied number of activities with an emphasis in promoting healthy lifestyles and accessing health care services. The Home Visiting Nurses provide case management/care coordination services to pregnant/postpartum women and children up to 2 years of age with medical/social risk factors. This activity ensures the most optimal health status for women with high risk conditions before, during and after pregnancy. Conditions such as diabetes, STDs, violence and others may be identified and the possibility of negative outcomes may be reduced, among them, prematurity, maternal and infant deaths. Pregnant teens are particularly targeted to guarantee their early entry into PNC and are followed throughout their postpartum period to assure that they receive family planning orientation. These activities are essential in our efforts to comply with several National and State Performances, new state priorities, and SOMs, among them, Priority 1 (Ensure an optimal state of health in women of reproductive age at the time of conception); Priority 3 (Decrease premature births); priority 7 (Promote healthy lifestyles in adolescents); SPM 1 (Proportion of women of childbearing age consuming folic acid); SPM 2 (Reduce the prevalence at birth of neural tube defects); NPM 15 (Percentage of women who smoke during the last three months of pregnancy); and NPM 18 (Percent of infants born to pregnant women receiving prenatal care beginning in the first trimester); and SOM 1 (the maternal mortality rate per 100,000 live births).

Another basic and essential activity carried out consistently is the educational component at all levels, individual, community and professional. This provides a fertile ground to raise awareness among the population on many pertinent health related topics. PRMCH Community Health Workers, HVNs, Health educators and other programs and agencies, private and public, collaborate in this endeavor. Some of the topics discussed are preconceptional use of folic acid, unintentional injuries prevention, oral health maintenance, asthma control, STD prevention, early PNC, among others. The educational activities constitute a pivotal component of almost all NPMs, SPMs and OM.

Foremost is also engaging actively in developing and maintaining surveillance systems and data collection surveys to monitor the health status of the MCA population. Several such systems are working currently and provide us with much needed information to delineate strategies to tackle the health issues we identify (See Section 1 Needs Assessment Process – Methods and Data Sources for details on surveillance systems). Priority 2 (Develop continuous and reliable data sources and surveillance systems) is developed to achieve this objective. Most NPMs, SPMs and HSIs are related to these activities, among them: SPM 3 (The degree to which the PRMCH collects, analyzes, and disseminates findings from data pertinent to ongoing target population health needs assessment); NPM 11 (The percent of mothers who breastfeed their infants at 6 months of age); and HSCI 9a (The ability of the state to assure PRMCH access to policy and program relevant information).

Another important activity is the development of public policy to assure the deliverance of consistent, comprehensive and accurate services. We have been successful in taking active part in the enactment of several laws pertaining PRMCH related matters. A clear example of this is NPM 11 (The percent of mothers who breastfeed their infants at 6 months of age). Several laws are currently being implemented in Puerto Rico to assure the breastfeeding rights of WRA and their offspring. This activity relates to two of our new priorities: Priority 1 (Ensure an optimal state of health in women of reproductive age at the time of conception); and Priority 4 (Decrease morbidity due to chronic conditions in the pediatric population).

Also, the collaborative efforts between the PRDOH, the PRMCH/CSCHN Programs, and other key stakeholders are vital to address the needs of the population we serve. One such joint effort is the March of Dimes Taskforce to tackle the problem of prematurity in the Island, which specifically relates to Priority 3 (Decrease premature births). The MCH Regional Boards are very important in the work done to enhance the health of target populations. In these boards representatives from government and non-government agencies work together sharing resources, coordinating educational activities and solving health-related specific situations of MCH populations. All our priorities, NPMs, SPMs, and HSIs are directly related to this activity.

In conclusion, the PRMCH is firmly devoted to improve the general well being of the maternal, child and adolescent population despite barriers that may be slowing down the process.

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PART II.

CSHCN POPULATIONS NEEDS

AND

SYSTEM CAPACITY ASSESSMENT

Puerto Rico CSHCN Needs Assessment

Background and Introduction

The purpose of Title V Children with Special Health Care Needs (CSHCN) programs is the development of comprehensive, family-centered, community-based, culturally competent, coordinated systems of care for children with special health care needs. The federal definition of CSHCN includes “*children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally*”.

Puerto Rico’s CSHCN program has not adopted the federal definition of CSHCN for planning and systems development. CSHCN eligible for services funded through Title V are a subset of this nationally defined population, and they must meet program-specific medical criteria (Table II-6).

Every five years, Puerto Rico Department of Health (MCH agency) is required to conduct a comprehensive needs assessment to identify Children with Special Health Care Needs (CSHCN) needs and prioritize them, and to evaluate the capacity of the existing system to provide and support needed health care needs and related services. The result of this process is a plan for directing limited resources to those priorities that are seen as most important, and a plan to measure progress in addressing them while the agency evolves from provider of direct services to a focus on promoting, monitoring and assuring quality of comprehensive systems of care for the CSHCN population. This document presents information on issues that affect the health status of the CSHCN population and Puerto Rico’s ability to address them, and an articulation of the priority needs that were identified through the needs assessment process.

Needs Assessment Process

Even though the PRDOH and other public and private agencies have conducted surveys among CSHCN families, a representative study of this population have not been conducted, nor is PR included in the National Survey of CSHCN. Our main goal for this needs assessment was to obtain representative data of Puerto Rico’s CSCHN population to better understand their needs, especially those related to the five CHSCN performance measures. Another goal was to obtain qualitative data about CSHCN families’ individual experiences and perceptions that could help us better understand the collected data. National CSHCN outcome measures formed the basis for the assessment framework. This outcome approach allowed us to see their collective relevancy and utility in improving the health status of the CSHCN population in Puerto Rico.

The methodology was developed by the CSHCN Staff, which includes an Epidemiologists and a Health Systems Evaluative Investigation Specialist. The staff participated in MCH Division’s general meetings to plan the overall need assessment process, discuss general methodology issues and follow-up activities. A strategic plan and timelines were developed to guide the needs assessment activities. The plan included the identification of

families and stakeholders who might collaborate and contribute to the needs assessment process.

The CSHCN Epidemiologist and the Health Systems Evaluative Investigation Specialist conducted the needs assessment. The epidemiologist was responsible of the design of the Puerto Rico Survey of Children with Special Health Care Needs (PRS-CSHCN) and coordination with the contractor that was to collect the data. The investigation specialist was in charge of the adaptation of the Spanish version of the National Survey of CSHCN questionnaire and the collection and analysis of qualitative data. Both of them worked with quantitative data documentation, analysis and report. The MCH anthropologist served as a consultant for the collection and analysis of the qualitative data.

The principal data source used to assess the characteristics of Puerto Rico's CSHCN population was the PRS-CSHCN. Other data sources were the 2007 and 2008 Individuals with Disabilities Education Act (IDEA) Child Counts, the Puerto Rico Birth Defects Surveillance System, and qualitative data collected through health conversations with mothers of CSHCN, stakeholders, MCH staff, and in-depth interviews to YSHCN. The Puerto Rico Survey of Children with Special Health Care Needs (2009) provided the first state-level data regarding prevalence estimates of children/youths with special health care needs (C/YSHCN), types of services they need and use, characteristics of the systems of care, health care coverage estimates and other data related to CSHCN performance measures in Puerto Rico. Continuation of such data collection will be essential to measure progress over time.

The PRS-CSHCN was conducted as a module similar to the State and Local Area Integrated Telephone Survey (SLAITS) from April through June 2009. The study used a revised and adapted Spanish version of the questionnaire used in the 2005-2006 National Survey of Children with Special Health Care Needs (NSCSHCN). Some questions were deleted because they did not apply to PR. (Example: the question about SSI benefits was deleted as this benefit is not available). Other questions were added (Example, CSHCN receiving services through the Department of Health's Pediatric Centers). The wording of some questions was revised and adapted. The questionnaire was computerized, validated and implemented by an independent contractor research company. The questionnaire was validated through a pilot test of 21 random telephone calls with parents of CSHCN. The mean duration of interviews was estimated in 45 minutes, with a range between 39 and 50 minutes. Changes that resulted from the pilot test results were related to question format and instructions but not to questions' content. Sample telephone numbers for each region were selected using the "Random Digit Dialing" (RDD) design approach.

The study used a stratified probabilistic sample representative of the seven health regions and the Island of Puerto Rico. Because it was the first time the study was implemented in PR, it was conducted in two phases. In phase 1, a sample of 1,000 household telephones was selected to estimate CSHCN prevalence, obtain preliminary demographic and geographic characteristics and complete the questionnaire from households with children that qualified as with special needs according to the screening questions. Information from the number of households with children in PR was obtained from the Census 2000.

Information from phase 1 was used to determine the sample size for each region to be completed on phase 2 based on the estimates of children with special needs by region. In phase two, 1,000 households with children and 1,692 children were screened for special needs. A total of 216 households with CSHCN and 272 CSHCN were identified. Additional households were screened during phase II to achieve the sample of 850 children with special health care needs. The total of telephone calls to reach the sample of 850 CSHCN was 134,200.

Methods to obtain qualitative data included health conversations with mothers of CSHCN, stakeholders, MCH staff, and in-depth interviews with youth with special health care needs. Some stakeholders participated in the identification of possible participants and others participated in the health conversations per se. A total of 4 health conversations were conducted with 34 participants. The qualitative information collected in these health conversations was recorded in a confidential manner and with the participants' verbal consent. Information was transcribed and analyzed through content analysis by organizing it into topics, categories, and case examples. These health conversations and interviews provided valuable information on needs and perceptions from the perspectives of CSHCN families, youth and stakeholders. In regards to YSHCN, the information was collected through individual in-depths interviews to five YSHCN between the ages of 23 and 28 (four males and one female). This age range was chosen to reduce memory bias while at the same time having participants that already completed their process to adult life. After getting their written consent, specific information was confidentially gathered on their needs, experiences, opinions, knowledge and perceptions regarding their transition process from the pediatrician to the adult physician. Information was also obtained on the barriers and facilitating factors that youth with special needs face during this process. Youth were selected on an intentional non-probabilistic sample basis for an in-depth semi-structured interview.

The CSHCN National Performance Measures (NPM) were used as starting point for assessing the Puerto Rico's capacity to provide and support needed health care needs and related services. The PRS-CSHCN indicators were used to assess accessibility, affordability and quality of the service system.

The final NA document will be shared with the Title V CSHCN Committee, which includes stakeholders from diverse public and private agencies and families. It will also be available through the Department of Health website. The needs assessment will be synthesized and disseminated to policy-makers to engage them in decision making about CSHCN priorities

The main strength of this needs assessment is the use of primary data sources, including the first PR Survey of CSHCN and health conversations with families and stakeholders. These data sources provided valuable information and a more complete picture of the needs of this population. Collaboration of diverse representatives from public, private and community-based organizations, families and persons with special needs in the identification of needs and determination of priorities is another strength. This group will continue to meet to address the selected priorities by developing and action plan with

strategies and activities. The main weakness of this needs assessment was the small number of participants in the health conversations.

Partnerships and Collaborations

Direct stakeholder input enriched and strengthened the content and validity of the CSHCN Five-Year Needs Assessment Process. The CSHCN Committee, composed of about 30 associations and diverse public and private agencies, corporate and nonprofit organizations, and CSHCN parents, participated in health conversations to collect qualitative data. Agencies represented in the health conversations included: the UPR Medical Science Campus, Metropolitan Pediatric Center, Government Citizenship Service Office, Rotaries' Wives Foundation for CSHCN (FERNI), Persons with Disabilities Ombudsman (OPPI), Administration of Health Insurance (ASES), Insurance Commissioner Office (HICO), CSHCN Parents' Association (APNI), San Juan City Hospital, Puerto Rican Pediatricians' Society, American Academy of Pediatrics PR Chapter, Rehabilitation and Education Society of PR (SER), PR University Center for Excellence in Developmental Disabilities (PR-UCEDD), Outreach Movement for Independent Living (MAVI), State Independent Living Council (CEVI), South Independent Living Center, (CEPVI), PR Developmental Disabilities Council (PRDDC), PR Assistance Technology Program (PRATP), and the Spina Bifida Association, among others. The Committee collaborated in the needs assessment and priorities selection processes and will collaborate in developing an action plan with strategies and activities to address them.

Characteristics of PR CSHCN Population

Based on the 2009 Puerto Rico Survey of Children with Special Health Care Needs, 16.6% of children from birth to 17 years have special health care needs. This percent translates to 180,889 children and youth with special health care needs according to 2000 US Census Puerto Rico population data. Prevalence of CSHCN ranges from 9.4% to 21.8% across the seven health regions (Caguas: 21.8%, Bayamón: 19.7%, Ponce: 18.7%, Metropolitan: 14.6%, Mayagüez: 13.1%, Arecibo: 12.3% and Fajardo: 9.4%). An estimated 1 in 4 (25%) of households with children have at least one child with a special health care needs. This translates to 124,031 households in PR.

Children with Special Health Care Needs are more likely to be in the age 6-11 years group, male and live in low income families. Twenty-five percent (25%) of CSHCN have one, 28.0% have two and 37.4% have 3 or more of the following conditions: Allergies: 48.6%, ADD/ADHD: 38.8%, Asthma: 35.6%, Depression, anxiety, or emotional problems: 28.9%, Migraine/frequent headaches: 21.2%, Developmental delay: 20.0%, Mental Retardation: 7.5%, Autism or Autism Spectrum Disorder: 5.9%, Heart Problems (including congenital heart disease): 5.3%, Epilepsy: 4.9%, Arthritis or other joint problems: 3.2%, Diabetes: 3.1%, Blood disorders: 2.5%, Cerebral Palsy: 1.5%, Muscular Dystrophy: 1.5%, Down Syndrome: 1.2% and Cystic fibrosis: 0.1%.

Ninety-three percent (93%) of CSHCN experience 1 or more of the following functional difficulties and 36.0% have 4 or more of these difficulties: Learning, understanding, or paying attention (ages 2–17 yrs old): 56.0%, Respiratory problems: 40.4%, Speaking, communicating or being understood: 35.7%, Feeling anxious or depressed: 32.1%, Chronic pain: 29.3%, Behavior problems: 28.4%, Difficulty seeing even with glasses: 23.8%, Making and keeping friends (ages 3–17 yrs old): 22.1%, Fine motor: 18.9%, Gross motor: 16.6%, Self care (ages 3-17 yrs old):16.3%, Swallowing, digesting food, or metabolism: 11.6%, Blood circulation: 3.4%, Uses a hearing aid: 14.8%.

Two factors to consider regarding a child's special health care needs are the severity of the condition and the extent to which that condition affects the child's daily life. Seventy-five percent (75.2%) of families reported 3 or more doctors visit for sick care in past 12 months. Sixty-eight percent (68.2%) reported 2 or more ER visits in the past 12 months. Forty-four percent (44%) of families classified their child's functional limitations as mild, 44.4% as moderate and 12.0% as severe. Thirty-four percent (34%) of families reported that their child activities are moderately affected part of the time while 11.4% report that their child activities are continuously significantly affected. Twenty-nine percent (29.0%) of CSHCN ages 5-17 years missed 11 or more days of school due to illness.

The type of health services required to manage a child's condition provides information about the extent of their special needs. Sixty-five percent (65.4%) of CSHCN needed or used a prescription medication, 61.8% needed or used medical, mental health or educational services, 54.0% needed or used specialized therapies and 30.9% had a limitation in activities.

Another indicator to assess the extent of CSHCN populations is the number of children with disabilities receiving early intervention services (birth to age 2, inclusive), and special education services under the Individuals with Disabilities Education Act (IDEA). The 2008 IDEA Part C Child Count indicated that 4,838 infants and toddlers, 3.43% of the population ages birth through 2, were receiving early intervention services. The 2007 IDEA Part B Child Count indicated that 9,644 (6.40%) of children ages 3 through 5 and 90,036 (96.64%) of children and youth ages 6 through 17 were receiving special education services. In the 3 through 5 years of age group, 8,284 (5.49%) have speech or language impairments, 323 (0.21%) specific learning disabilities, 295 (0.20%) other health impairments, 256 (0.17%) autism, 149 (0.10%) mental retardation, 136 (0.09%) multiple disabilities, 63 (0.04%) hearing impairments, 43 (0.03%) orthopedic impairments, 43 (0.03%) visual impairments, 32 (0.02%) emotional disturbance, and 10 (0.01%) developmental delay. In the 6 through 17 years age group, 51,263 (7.26%) have specific learning disabilities, 8,502 (1.20%) mental retardation, 5,624 (0.80%) other health impairments, 1,216 (0.17%) autism, 1,125 (0.16%) emotional disturbances, 924 (0.13%) multiple disabilities, 653 (0.09%) hearing impairment, 448 (0.06%) orthopedic impairments, and 10 developmental delay.

Another source of information used to identify the extent of Puerto Rico CSHCN population is the number of cases with birth defects identified by the Puerto Rico Birth Defects Surveillance System. In 2007, 904 cases of birth defects were detected among live born infants and fetuses of 20 or more weeks of gestation. The incidence rate per 10,000 live births was 17.12 for Talipes Equinovarus, 12.63 for Down syndrome, 11.99 for Cleft Lip and/or Palate, 5.99 for Limb Reduction Defects, 5.57 for Spina Bifida, 5.57 for Pulmonary Valve Stenosis, 4.07 for Trisomy 18, 3.64 for Coartation of the Aorta, 3.00 for Hypoplastic Left Heart Syndrome and 3.00 for Atrio-Ventricular Canal. In 2006, birth defects were the leading cause of infant mortality in the “1,500-2,500 grams” and “2,500 or more” groups. The birth defects that contributed the most to infant mortality were heart defects and trisomy 18.

Capacity Assessment

Direct Health Care Services

Direct Health Care Services are services generally delivered one-on-one between a health professional and a patient in an office, clinic or emergency room. For CSHCN these services include specialty and sub-specialty care for those with HIV/AIDS, hemophilia, birth defects, chronic illness, and other conditions requiring sophisticated technology, access to highly trained specialists, or an array of services not generally available in most communities.

In order for services to be of value to CSHCN and their families, the system must be organized in such a way that services are provided in accessible and appropriate contexts, and that there is a family-friendly mechanism to pay for them. Based on PRS-CSHCN data, the CSHCN outcome of community-based service systems easily organized so families can use them easily was successfully achieved for 81.8% of CSHCN (vs. 89.1% nationwide).

Unmet needs are an important measure of access to health care services. The PRS-CSHCN revealed that during the last 12 months, 19% of CSHCN had 1 unmet need and 11.5% of CSHCN had 2 or more unmet needs for the following 15 specific health care services or equipment (Percents are based on parental reports of needing the service and not receiving it, in descending order).

Communication aids or devices, such as communication boards:	52.6% (n=7) (Weighted Estimate = 1604)
Substance abuse treatment or counseling:	35.1% (n=1) (Weighted Estimate = 232)
Physical, occupational or speech therapy:	23.0% (n=100) (Weighted Estimate = 21720)
Hearing aids or hearing care:	20.4% (n=13) (Weighted Estimate = 2822)
Mental health care or counseling:	15.9% (n=19) (Weighted Estimate = 4256)
Genetic tests:	14.2% (n=22) (Weighted Estimate = 4512)
Mobility aids or devices such as canes, crutches, wheelchairs, or scooters:	13.1% (n=4) (Weighted Estimate = 859)
Specialty doctor care:	13.0% (n=72) (Weighted Estimate = 15533)
Other dental care:	11.3% (n=18) (Weighted Estimate = 4051)
Eyeglasses or vision care:	10.8% (n=26) (Weighted Estimate = 5324)

Routine preventive care:	6.8% (n=41) (Weighted Estimate = 9297)
Medical supplies:	5.2% (n=3) (Weighted Estimate = 663)
Prescription medications:	4.5% (n=31) (Weighted Estimate = 6715)
Preventive dental care:	4.3% (n=29) (Weighted Estimate = 6315)
Durable medical equipment:	3.5% (n=3) (Weighted Estimate = 484)
Home health care:	0.8% (n=1) (Weighted Estimate = 235)

The more common reasons for unmet communication aids needs were: no health insurance coverage (14.8%), no or late referrals (14.7%) and high costs (14.5%). Similar reasons were found for hearing aids and mobility devices: Hearing aids: no or late of referrals (25%), high costs (25%) and not covered by health insurance (16.8%), Mobility devices: not covered by health insurance (50.3%), High costs (50.3%) and no or late referrals (22.6%). When it comes to physical, occupational and speech therapy the most cited reasons were late referrals (28.2%) and school lack of resources (24.2%). For genetic tests the reasons cited were test not covered by health plan (32.4%) and high costs (28.3%). Finally, for medical specialist care the reasons cited were not covered by health plan (34.3%), no or late referrals (22.2%), high costs (17.6%). For mental health care services and substance abuse treatment no single reason stands out.

PRS-CSHCN data also revealed that during the last 12 months, 37.3% of CSHCN under the GIP had 1 or more unmet needs versus 21.5% of CSHCN with private health insurance, a statistically significant difference ($p=.000$). PRS-CSHCN also found that 53% CSHCN families had small or large problems getting a referral for needed specialty care (vs. 22% nationwide). The percentage for families under the GIP was 61.5% versus 35.5% for families with private health insurance, a statistically significant difference ($p=.000$). CSHCN Committee stakeholders as well as mothers of CSHCN participating in health conversations identified difficulties getting referrals under the GIP basic coverage as one of the main barriers to needed services. A mother with a child under the Government Insurance Plan (GIP) basic coverage was the person with more complaints. She did not know about the GIP special coverage. She expressed: "...God knows all the benefits that our children have but we do not know about..." and was convinced that if her son had another health plan, he would have already undergone surgery for his scoliosis. She also complained of difficulties in getting referrals and in communicating with some pediatricians. Another mother with her baby under the GIP special coverage had no complaints at all and expressed complete satisfaction with services, referrals, coordination of services and communication with her physicians. She expressed: "...look! With the special coverage, for everything, I do not pay a penny here or anywhere else, and have no problems with referrals." The major complaint of a mother with a baby under both private health plan and GIP was her communication with the specialist (surgeon). She expressed: "...when a person talks to you like that, you know, you repress yourself, you are afraid to ask any question."

The YSHCN study participants under the health insurance provided by the government (GIP) have also encountered the most difficulties accessing services. Among these: the GIP renewal process; getting and processing referrals, frequent changes of physicians; long processes for the authorization of certain interventions, and physicians and healthcare

professionals that are not well informed about the GIP processes. A long waiting time for CSHCN to be seen by a pediatric specialist or sub-specialist due to shortages of professionals, especially geneticists and dermatologists was another barrier identified by CSHCN Committee stakeholders

The number of pediatric specialists and sub-specialists was assessed with information from the Puerto Rican Pediatric Society. Most pediatric specialist have their offices in the Metropolitan Area: Cardiologists: 10 (five in the Metro Area), Surgeons: 10 (seven in the Metro Area), Dermatologists: 2, Endocrinologists: 10 (seven in the Metro Area), Physiatrists: 5 (four in the Metro Area), Gastroenterologists: 11 (six in the Metro Area), Geneticists: 5, Nephrologists: 9 (five in the Metro Area), Pneumologists: 10 (five in the Metro Area), Neurologists: 15 (eight in the Metro Area). Neonatologists: 10 (four in the Metro Area), Ophthalmologists: 10 (eight in the Metro Area), Orthopedics: 6 (five in the Metro Area).

According to the PRS-CSHCN, approximately 97% of CSHCN were insured at the survey time. Over half children (53.8%) have the Government Insurance Plan, (51.1%) have insurance through parents' employment, 1.4% has a military health plan, and 4.3% have another plan that covers health services. An estimated 10% were uninsured at some time over the previous 12 months.

One of the MCHB Title V performance measures is that families will have **adequate** private and/or public insurance to pay for the services they need. The PRS-CSHCN revealed that 40.8% of families feel that their insurance coverage is adequate for their child's needs (Nationwide: 62.0%). Approximately 48.2% of parents reported that out of pocket costs are never or sometimes reasonable, 25.2% reported that child's insurance plan never or sometimes covered their child's needs; and 25.1% reported that the insurance never or sometimes allowed child to see needed providers. Many genetic and metabolic assays are excluded from the GIP benefit packet. Families strive to pay for these expensive tests out of their pocket so the diagnosis is confirmed and their children have an opportunity to be included in the GIP special coverage. Stakeholders also brought their concern about the challenge to obtain mobility aids or devices for these children. Most of the health insurance companies in PR do not cover this kind of equipment.

YSHCN expressed their concerns about getting uninsured when starting a job. Most of them expressed that their job does not pay enough for them to get an adequate health insurance plan, but at the same time their jobs make them ineligible for the GIP. They also expressed that when they are in the GIP renewal process (every six to 12 months), the complexity of the process and the bureaucracy have sometimes caused temporary lack of health coverage. One of them expressed: "I believe that issues about the health of people should be somewhat faster because in a split second, we have conditions that can change our lives."

There is a strong relationship between health insurance coverage and access to health care. Insurance coverage for CSHCN in Puerto Rico is not optimal, as evidenced by 10% of

CSHCN who were without health insurance at some point during a one-year period and 59.2% who reported that their current insurance was not adequate.

MCHB has established a goal of having CSHCN receive coordinated comprehensive care through a medical home. Data from the PRS-CSHCN revealed that only 24.7% of CSHCN ages 0 to 18 years receive coordinated, ongoing, comprehensive care within a medical home (Nationwide: 47.1%).

Access to care coordination is one of the components included in the medical home construct. Care coordination is critical for many families in the management of their child's health care and is a key issue in a medical home. The PRS-CSHCN revealed that 41.4% of families benefit from effective care coordination. Other items included in the medical home construct related to care coordination are: doctor-to-doctor communication and doctors' communication with other programs. Fifty four percent (54%) of families reported to be very satisfied with physician-to-physician communication and 49.4% of families reported to be very satisfied with physician communication with other programs. Two other components of the medical home construct are: CSHCN has a personal doctor or nurse who knows them well and CSHCN has a usual source of care. Ninety five percent (95%) of families reported having a personal doctor and 77.8% having a usual source of sick and well care.

Other components of the medical home are the accessibility to family-centered care services and needed referrals. Physicians that provide family-centered care services are health professionals with the capacity to listen carefully dedicate time, are sensible, provide the family with the necessary information, and make family feel like a partner in child's care. On indicators of family-centered care, 81.7% of families reported that physicians usually or always spent enough time, 88.1% reported that physicians usually or always listened carefully, 82.3% reported that physicians were usually or always sensitive to values and customs, 83.2% reported that physicians usually or always provided needed information, and 87.7% that the physician made them feel as partners. Nevertheless, 53.1% of families reported to have big or small problems to get needed referrals.

Another MCHB outcome is the percentage of families that feel like partner in decision-making and that are satisfied with the services they received. Based on PRS-CSHCN data, 38.7% families of CSHCN ages 0 to 18 years feel like partners in decision making at all levels and are satisfied with the services they receive (vs. 57.4% nationwide). Overall, 87.7% of families reported that they usually or always feel being participants in decision-making and on satisfaction with services, 39.5% of CSHCN families reported to be very satisfied with the services received. Thirty three (33%) of CSHCN families under the GIP reported satisfaction with the services versus forty eight (48%) of families with private insurance, a statistically significant difference ($p=.000$).

Stakeholders and families expressed their concern about the lack of counseling to CSHCN families, especially on issues of how to cope with the impact that a special child brings to a family. Other concerns brought by stakeholders in relation to care coordination is the lack of knowledge of some health professionals about available services, and possibly an

attitude of apathy to go the extra mile and look for a needed service. Some mothers complained about the time they have to wait, especially in the specialists' offices and recommended that health professionals be educated on this issue. They also complained about the lack of sensitivity of some public agencies that do not listen nor considerate their children as priorities. YSHCN most of them expressed themselves as being very grateful to their pediatrician. The main reason cited was that "they were educated by their pediatrician about his/her condition and how to manage it". Other commentaries were "my pediatrician saved my life", "my pediatrician was one of the most important persons in my life", "...she helped me to reach my achievements".

Enabling Services

Enabling services allow or provide access to and the derivation of benefits from, the array of health care services. These services are specially required for the low income, disadvantaged, geographically or culturally isolated, and those with special and complicated health needs. For CSHCN these services include transportation, care coordination, translation services, home visiting, and family outreach. Family support activities include parent support groups, family training workshops, advocacy and social work.

Transition

MCHB performance measures for CSHCN include that youth with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence. Puerto Rico has struggled to provide the services necessary to help CSHCN transition to adulthood. PRS-CSHCN data shows that 26% of youth with special health care needs receive the necessary services (vs. 41.2% nationwide). PRS-CSHCN data for the three indicators regarding transition to adulthood health care revealed: 54% of pediatricians have talk about having eventually see doctors or other health care providers who treat adults, 64.3% of pediatricians have talk about health care needs as an adult, and 27% reported that the pediatrician talked about obtaining an adequate health insurance as an adult. Also, 76% of families reported that the pediatrician usually or always promotes the young child to be responsible of his/her own health and care.

What did youth say about transition? Participants reported to perceive health not only as a physical well-being but also the mental stage, the relationship with their surroundings, exercises and good nutritional habits, and avoid stress. They also reported on perceiving transition to adulthood as a process, a stage of growth and development leading to changes, adaptations, freedom and responsibilities, and that it is not easy and must be supported by family. One youth said: "This is like a ladder where you say to yourself: 'Oh, I'm tired... oh, I can't, I'm getting more tired, oh look! I'm closer, I'm getting it, a little bit more...I got it!'". When asking youth about their pediatric health professional informing them on transition for a health care adult, three participants reported not to remember if they had any counseling from their pediatric physician at all, about their transition to an adult physician. They said that basically their mothers were in charge of this process. Two other participants reported to have received this counseling from their pediatrician at about the age of 18.

Transportation

Transportation is a non-clinical service specifically linked to a medical encounter or provision of medical services that aims to increase access to care, and to improve health outcomes. PRS-CSHCN found that twenty three percent (23%) of families reported not having access to needed services due to lack of transportation. Stakeholders also identified transportation as a barrier for families that live in rural or isolated areas. Some municipalities have transportation services for persons with disabilities but they are limited, as one of the stakeholders explained. One YSHCN reported that “Llame y Viaje”, a state transportation system for persons with disabilities in the San Juan Metropolitan Area, is not completely reliable.

Respite Care

Respite care is another support service for CSHCN families. PRS-CSHCN data revealed that 48.8% of families that needed respite care services did not receive them. “Respiro de Puerto Rico, Inc.” is only one entity that offers respite service in PR.

Family Support

YSHCN participants gave great significance to family support as a key element for their achievements. One of the participants pointed out that for the families to be of support, they need in turn to have accessibility to parent support groups, they need to be informed, and the physicians must listen to their concerns. Identified barriers included lack of guidance and information for families; low expectations from families and society in general, and prejudice. Another expressed the importance of family support: "... this is the frustration, the pain, the suffering ... the anger ... I have family but I don't have their support...". However, the facilitating factor more commonly expressed was family support: "...if I would not have had a good family base, I would not have been able to face these challenges...."

Population-Based Services

Population-based services include preventive interventions and personal health services, developed and available for the entire MCH population of the State rather than for individuals in a one-on-one situation. Disease prevention, health promotion, and statewide outreach are major components. These services are generally available whether the mother or child receives care in the private or public system, in a rural clinic or an HMO, and whether insured or not.

Newborn Metabolic Screening Program

In Puerto Rico, newborns are screened for 5 conditions: phenylketonuria (PKU), congenital hypothyroidism, galactosemia, classical congenital adrenal hyperplasia and sickle cell disease. Follow up is very successful, with 100% of those needing treatment receiving it. Puerto Rico is currently expanding its program to include 20 additional conditions detectable via Tandem Mass Spectrometry (MS/MS).

Universal Newborn Hearing Program

In Puerto Rico, is mandatory for all newborn to receive hearing screening and all health insurers are required to cover the screening. In 2009, 98.4% of newborns received hearing

screening. Of these, 2.52% were referred for audiological evaluation. The program has a grant from the Health Resources and Services Administration for reducing loss to follow-up after failure to pass newborn screening.

Infrastructure-Building Services

Infrastructure–Building services refers to activities directed at improving and maintaining the health status of all women and children, including children with special health care needs, by providing support for development and maintenance of comprehensive health services systems including development and maintenance of health services standards/guidelines, training, data and planning systems. Examples include needs assessment, evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care. In the development of systems of care it should be assured that the systems are family centered, community based and culturally competent. For CSHCN, the activities include the following four constructs of a service system: 1) State program collaboration with other state agencies and private organizations, 2) State support for communities, 3) Coordination of health components of community based systems and 4) Coordination of health services with other services at the community level.

Family Centered, Community Based, Coordinated and Culturally Competent Services

Puerto Rico's CSHCN program has not adopted the federal definition of CSHCN for planning and systems development. Other than direct services for a subset of the nationally defined CSHCN population and the required Five-Years MCH needs assessments, the CSHCN program has not taken a leadership role in other activities such as evaluation, planning, policy development, coordination, quality assurance, standards development, monitoring, training, applied research, information systems and systems of care for the CSHCN population. It was last year that a parent-staff was recruited for the first time. The reason, Title V funds have been primarily used for direct health care services.

This fact is now haunting the Program as current Title V and program income funds have resulted in a limitation of the specialized services provided and a decrease in the number of CSHCN served. During fiscal years 2004-2007, the mean population served by the Program was nearly 8,100 CSHCN. The total number served during 2008-2009 was 6,444, a reduction of 20% compared to previous years. This issue was brought to the Secretary of Health and a complete evaluation of the CSHCN program is currently underway.

Data collection

The CSHCN Program has strived for various years to have representative data of the CSHCN population in the island in order to know their needs and identify well targeted strategies and activities. For the first time the CSHCN Program was able to conduct a CSHCN survey similar to the national survey. The challenge now is to conduct the survey every four to five years to assess progress and emerging issues.

Programs collaboration

Avanzando Juntos, Puerto Rico's Early Intervention Services System under Part C of IDEA, and the CSHCN Program, have a longstanding collaborative relationship. Avanzando Juntos System's Points of Entry, one in each health region, are located in the CSHCN program Regional Pediatric Centers (RPC). The CSHCN-RPC staff participates in eligibility, assessments and ISPF development and implementation activities, and also provides administrative support. The CSHCN program also participates in Avanzando Juntos child finds activities. Children referred to the CSHCN program that are experiencing developmental delays or a diagnosed physical or mental condition which has a high probability of resulting in developmental delay are referred to Avanzando Juntos. The same applies to infants and toddlers referred to Avanzando Juntos that are medically eligible for CSHCN program services. CSHCN program services are also included in the child's Individualized Family Service Plan (IFSP).

The BDSS is a population-based active surveillance system that assesses approximately 45,000 births each year. All PR birthing hospitals are visited weekly by the abstractors; and 99.7% of babies are born in these hospitals. This surveillance system compiles epidemiologic data for forty four (44) congenital conditions. One of the strengths of this data source is that is an active surveillance system. The program's data abstractors and genetic counselor refer to the CSHCN program those children that meet the medical eligibility criteria. The Universal Newborn Hearing Screening Program (UNHSP) is another program that provides information of the CSHCN program as an option for families of newborns identified in need of audiological evaluation and/or treatment.

Priorities Selection

As first step, the CSHCN staff identified eight potential priorities based on the needs assessment results. The selected potential priorities were: 1) increase the number of CSHCN with adequate health insurance; 2) improve the referral process; 3) develop continuous and reliable data sources about CSHCN and their families; 4) increase the number of CSHCN that have coordinated care, 5) increase the number of CSHCN that receive family-centered care, 6) increase accessibility to specialists, 7) increase the number of CSHCN families that are well informed and empowered, and 8) increase the number of YSHCN that are well informed on their transition to adult life.

A body of stakeholders was convened on April 22, 2010 to present the results of the first Survey of CSHCN in PR and to discuss the potential priorities identified by the CSHCN staff. Opportunity was provided for discussion of any other potential priority. An instrument was developed for stakeholders to rank the potential priorities. The participants then completed information on available resources to address each priority. For the selection of the final priorities the values assigned to each priority were added and the five priorities with the highest values were selected.

The five priorities with the highest ranking in descending order were:

1) Increase the number of CSHCN with adequate health insurance.

- 2) Increase the number of empowered CSHCN families by promoting family competency to identify and manage their child needs through family centered-care.
- 3) Increase the number of CSHCN that receive coordinated care services.
- 4) Development of continuous and reliable CSHCN data sources or surveillance system.
- 5) Increase the number of YSHCN that are well oriented for their transition to adult life.

The three prior CSHCN priorities resulting from the 2005 needs assessment were:

- 1) Increase availability and accessibility to high-quality preventive and primary health care services for the CSHCN population.
- 2) Improve coordination among health care plans, primary physicians and the Pediatric Centers
- 3) Promote successful transition of youth to adult life.

The final three CSHCN priorities selected based on the 2010 needs assessment data and CSCHN program capacity are:

- 1) Increase the number of empowered CSHCN families by promoting family competency to identify and manage their child needs through family centered-care.

This is a new priority. In each of the health conversations and almost all YSHCN interviews the importance of empowered and informed families was brought up. Stakeholders also ranked it as the second most important issue to address. This priority is related to direct health care services and infrastructure-building services of the pyramid. Outcome will be measured by National Performance Measure #3: The percentage of CSHCN that receive comprehensive, coordinated, and family-centered services through medical homes; and by National Performance Measure #2: Families that partners in decision making.

- 2) Increase the number of CSHCN that receive coordinated care services.

This priority continues from the previous needs assessment “Improve coordination among health care plans, primary physicians and the Pediatric Centers”. Care coordination is one component of the medical home. This priority is related to direct health care services and infrastructure-building services. The 2010 needs assessment revealed that care coordination is our weakest medical home component. Outcome will be measured by National Performance Measure #3: The percentage of CSHCN that receive comprehensive, coordinated, and family-centered services through medical homes.

- 3) Increase the number of YSHCN that are well oriented for their transition to adult life.

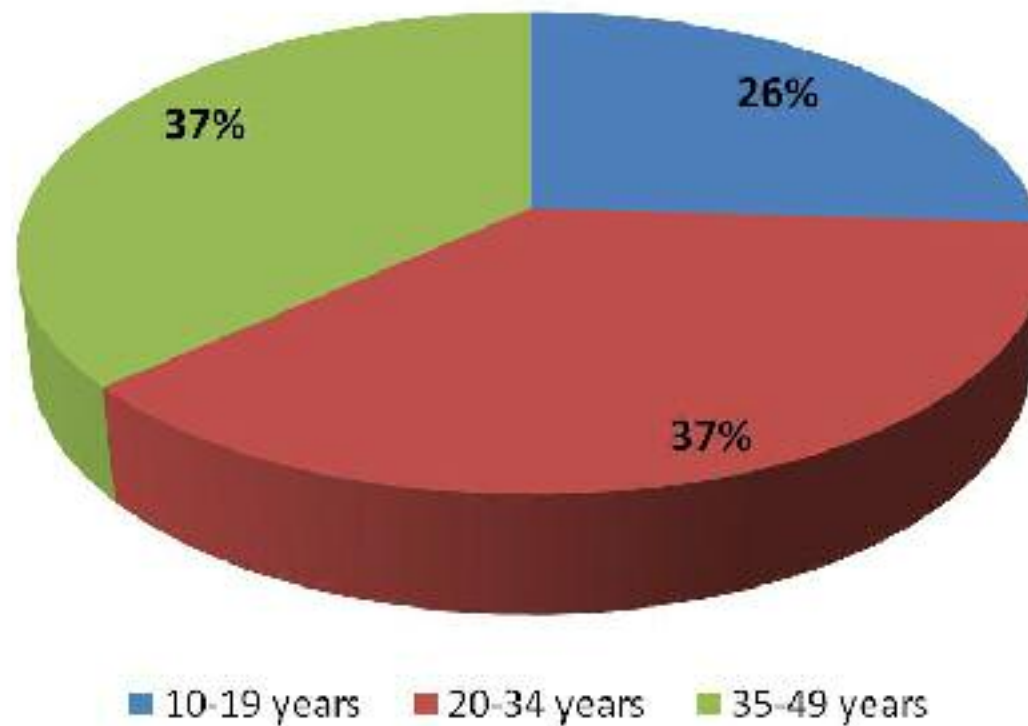
This priority continues from the previous needs assessment. Transition services are enabling services. PRS-CSHCN data shows that only 26% of youth with special health care needs receive the necessary services. Outcome will be measured by National Performance Measure #6: The percentage of YSHCN who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

One of the remaining potential priorities, development of continuous and reliable CSHCN data sources or surveillance system will be addressed under MCH priority “Develop continuous and reliable data sources and surveillance systems”. The other potential priority was increasing the number of CSHCN with adequate health insurance. This priority includes two other initial potential priorities: improving the referral process and increase accessibility to specialist. It is also related to the 2005 priority: Increase availability and accessibility to high-quality preventive and primary health care services for the CSHCN population. This priority was replaced. Although adequate health insurance is a high priority CSHCN need, the CSHCN program currently does not have the capacity to address it in a meaningful way as the issue was too broadly focused. However, the CSHCN program will follow up with ASES as changes to the GIP are underway under Obama’s Administration Health Reform.

APPENDIX

Figure II-1

Women in Reproductive Age by Age Group Puerto Rico: Year 2007

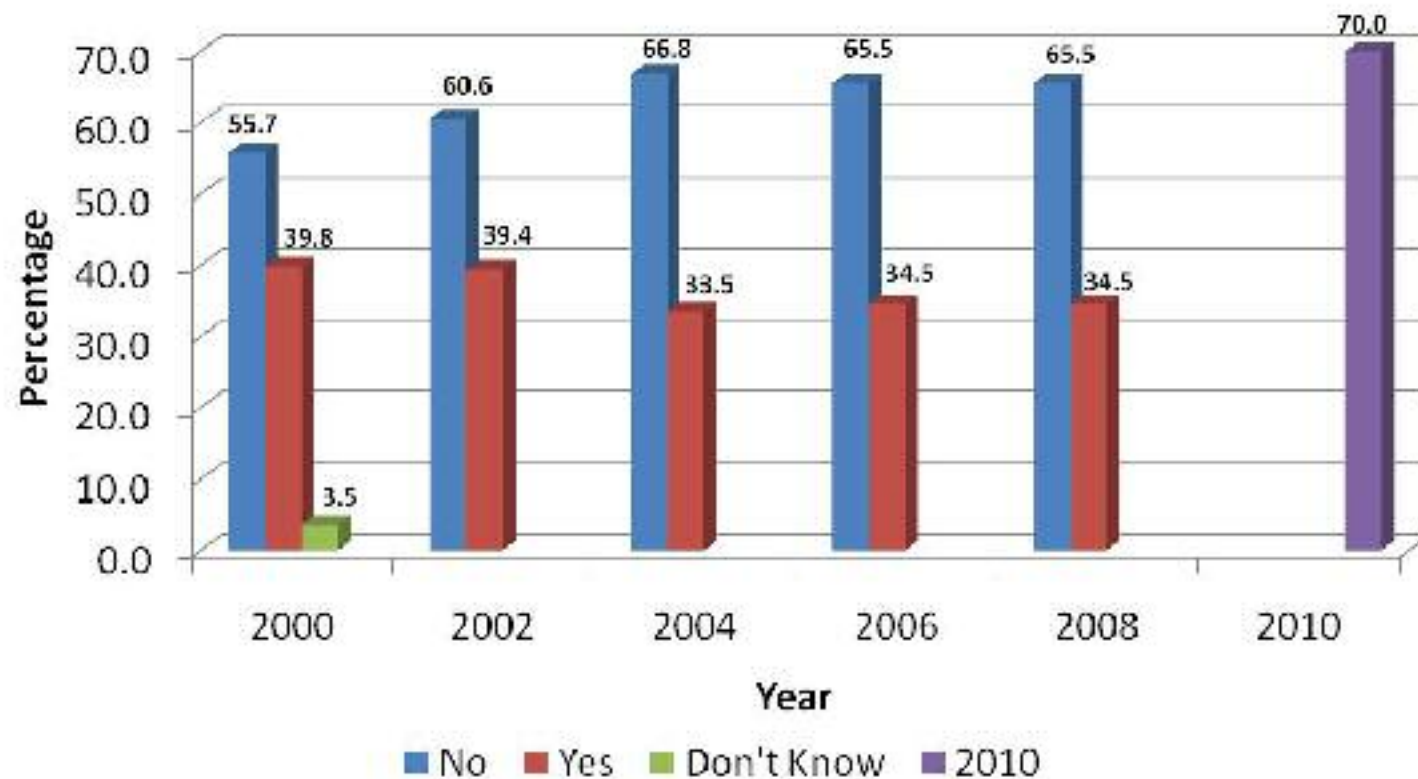


Source: Puerto Rico Community Survey, 2007.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-2

Puerto Rico Maternal-Infant Health Survey (ESMIPR) Was this pregnancy planned?

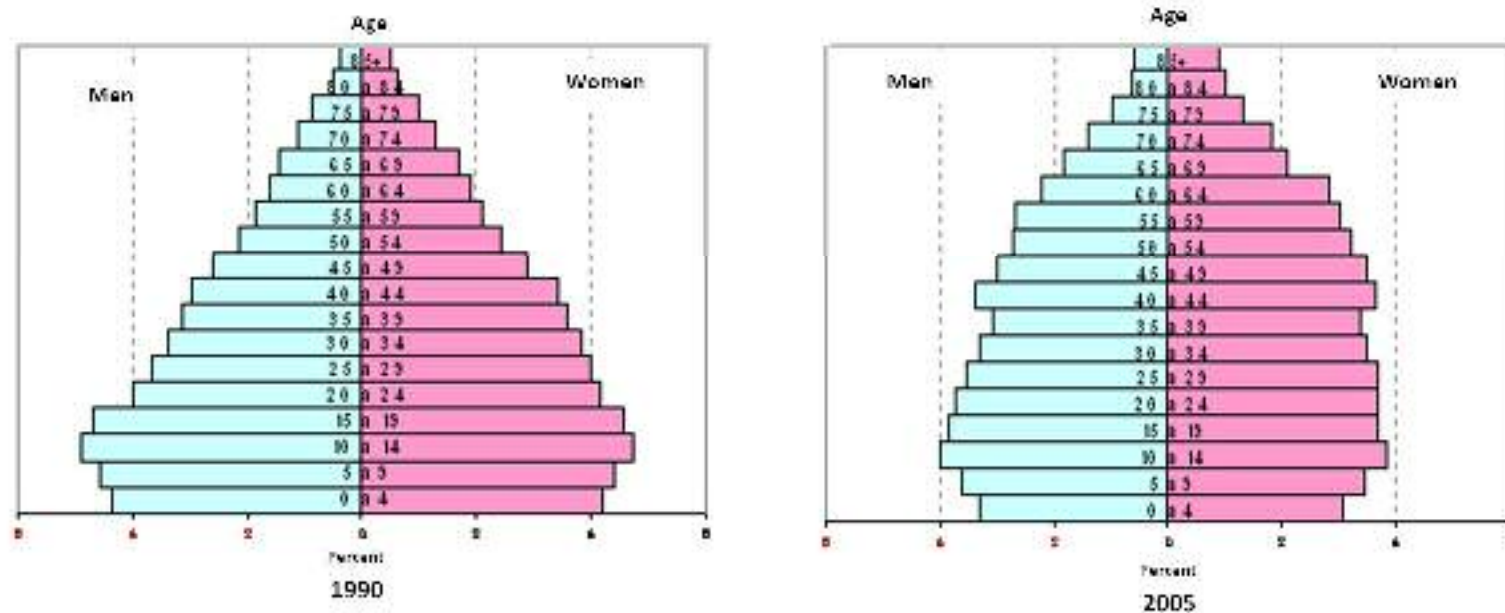


Source: ESMIPR 2000, 2002, 2004, 2006 and 2008.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-3

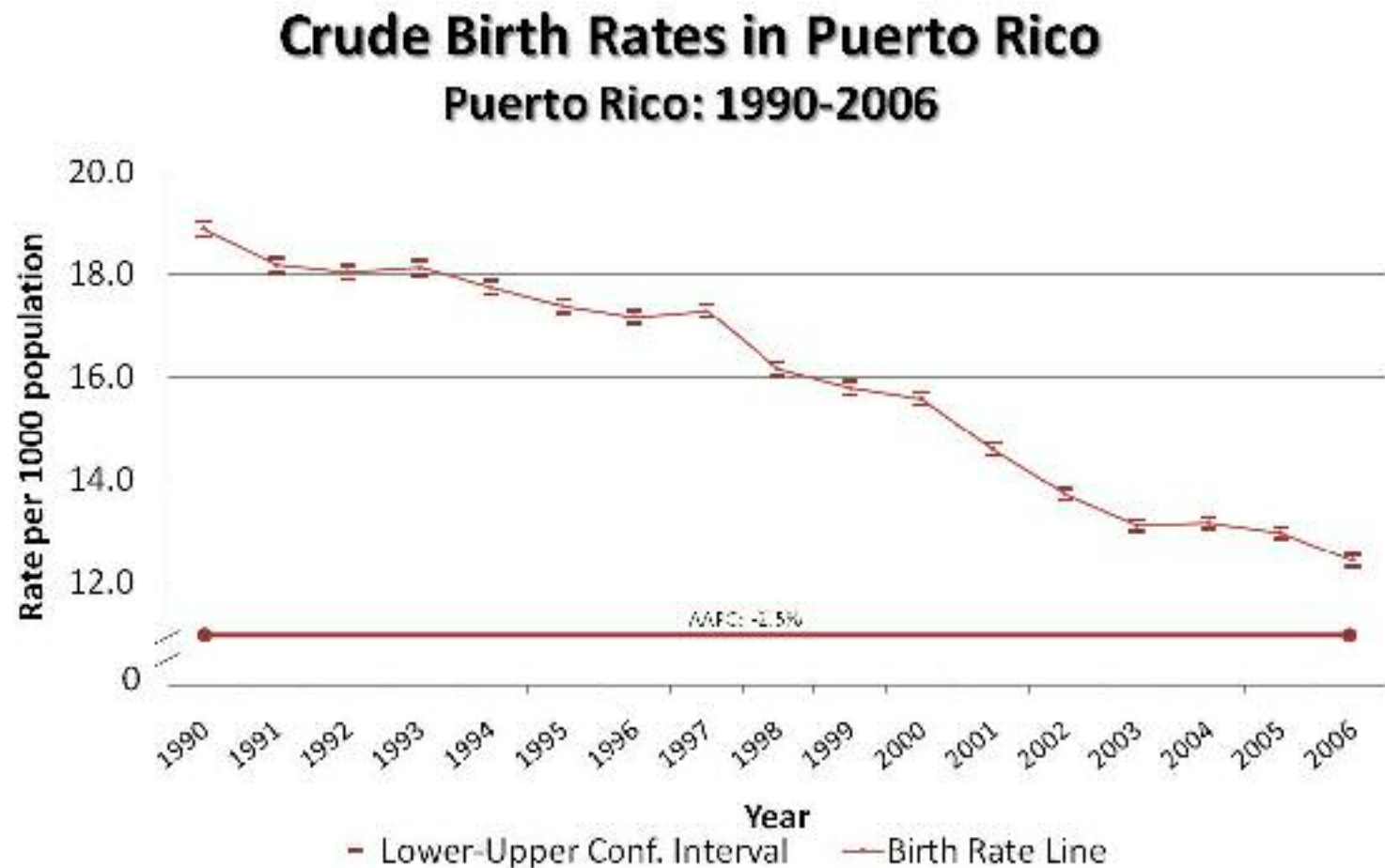
Puerto Rico Population Pyramid 1990 vs. 2005



Source: Census 1990; Census Population Estimates 2005.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-4



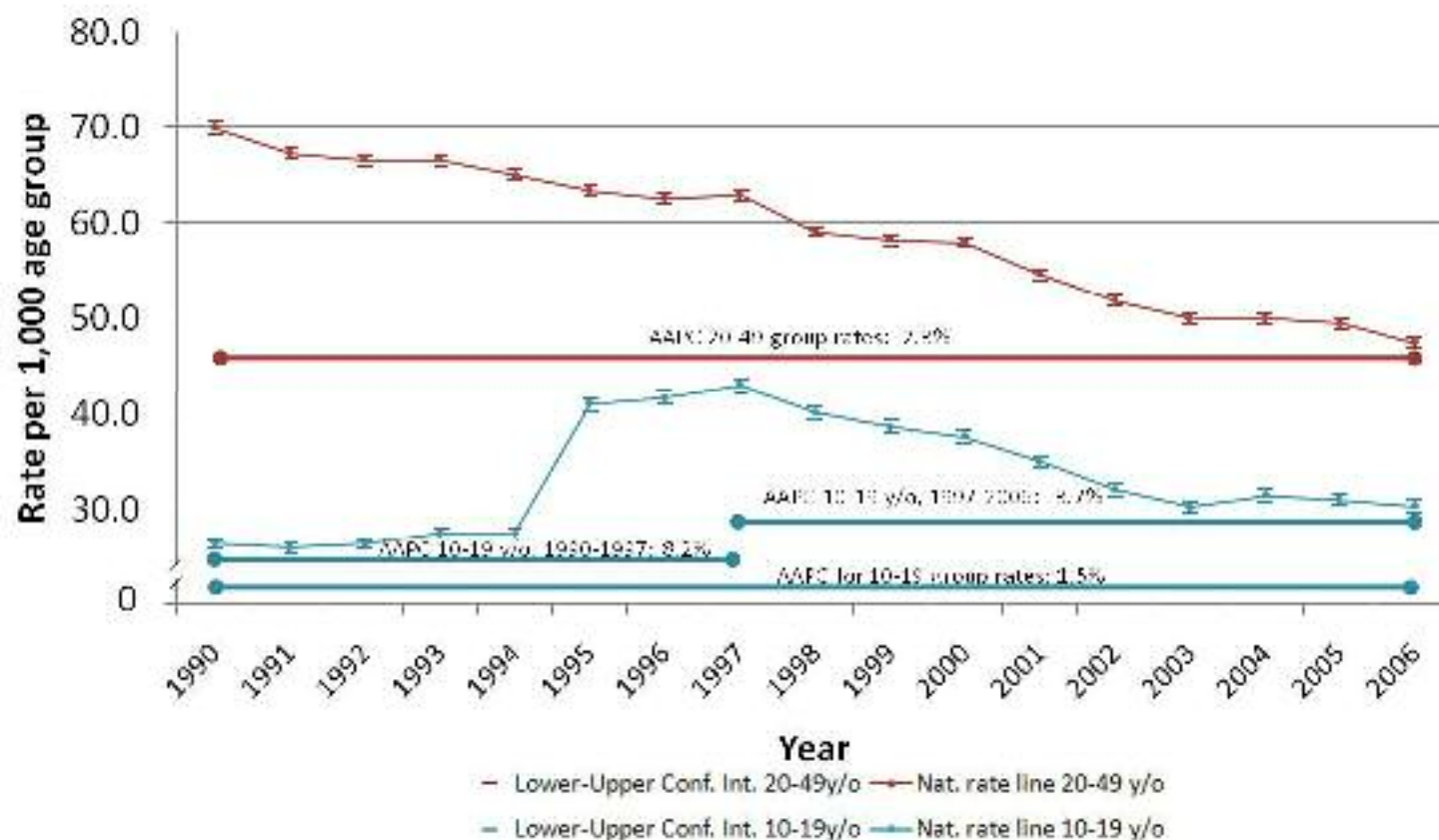
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-5

Specific Birth Rates by Age Group Puerto Rico: 1990-2006



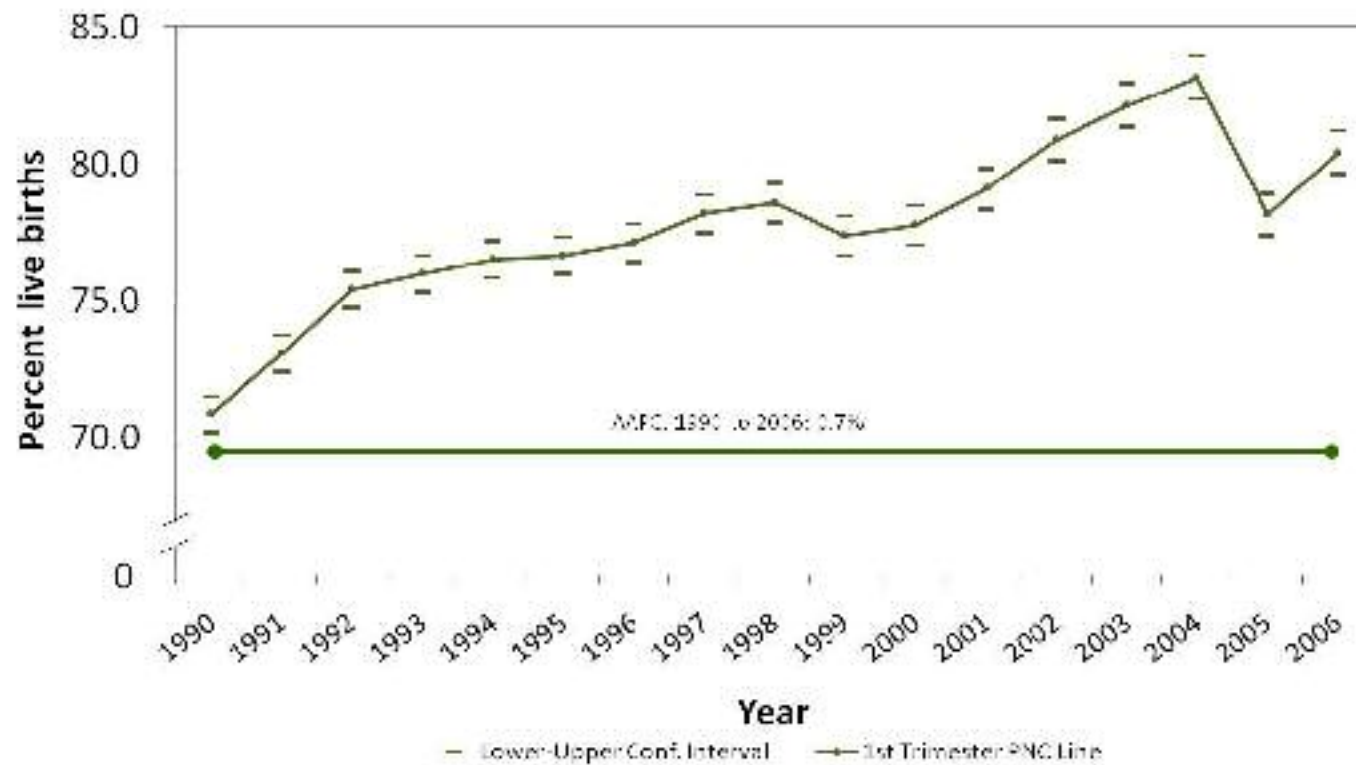
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-6

Prenatal Care during First Trimester of Pregnancy Puerto Rico: 1990-2006



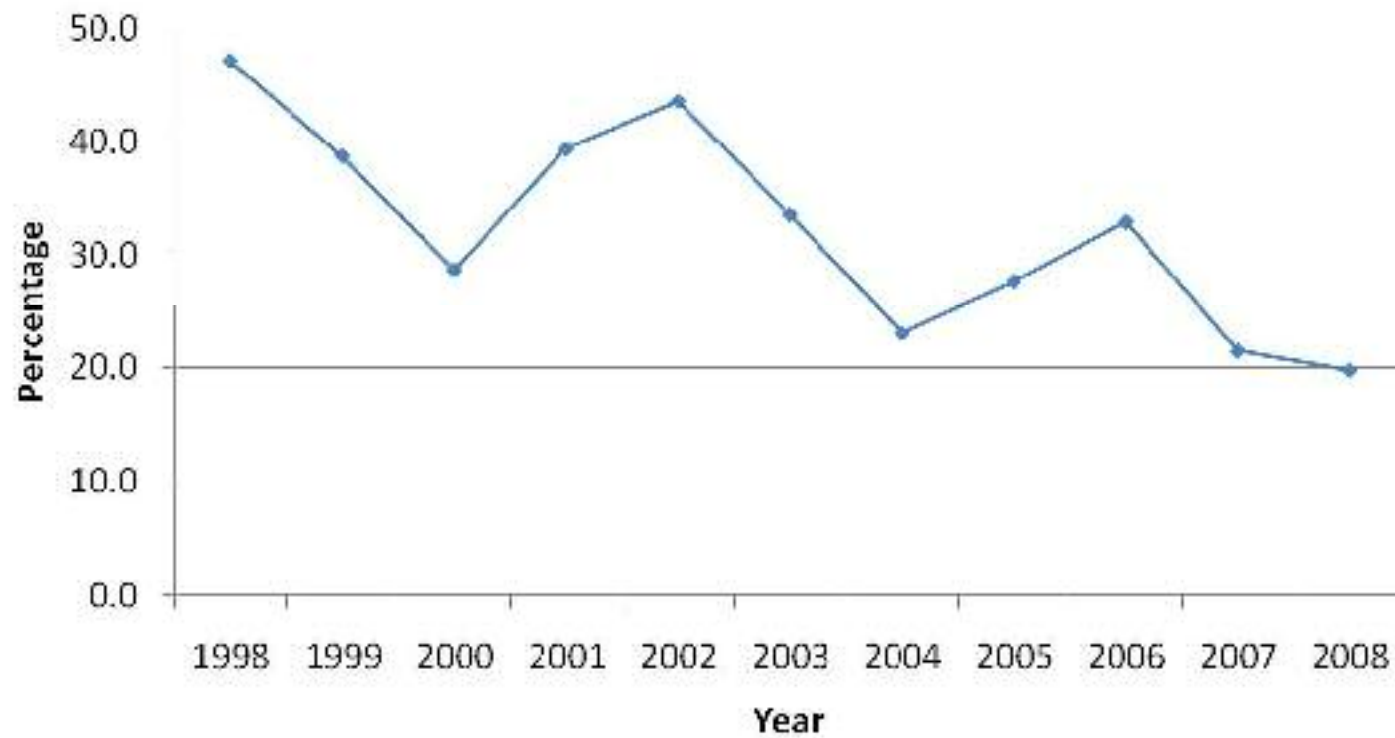
Source: Puerto Rico Department of Health, Vital Statistics Data 1990-2006.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-7

Congenital Syphilis

Puerto Rico: 1998-2008

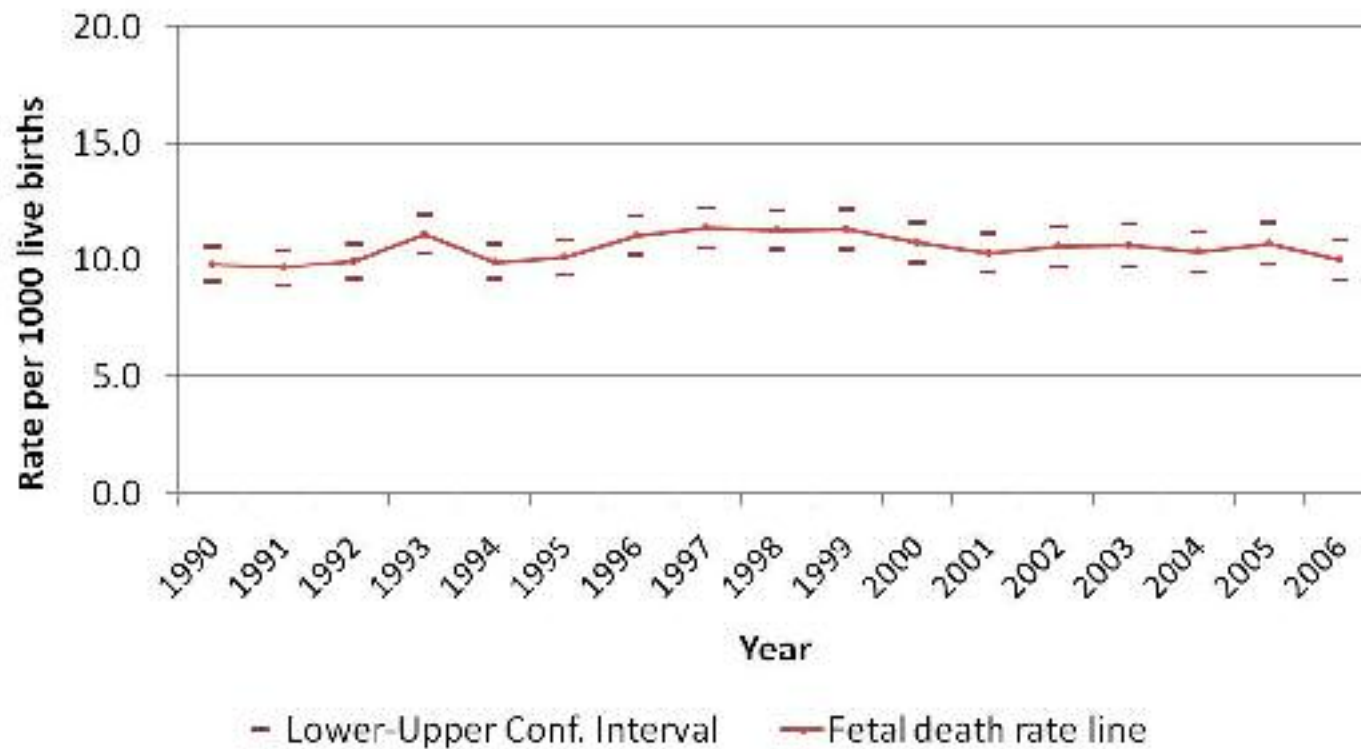


Source: Puerto Rico Department of Health, STD Surveillance.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-8

Fetal Mortality Rates

Puerto Rico: 1990-2006

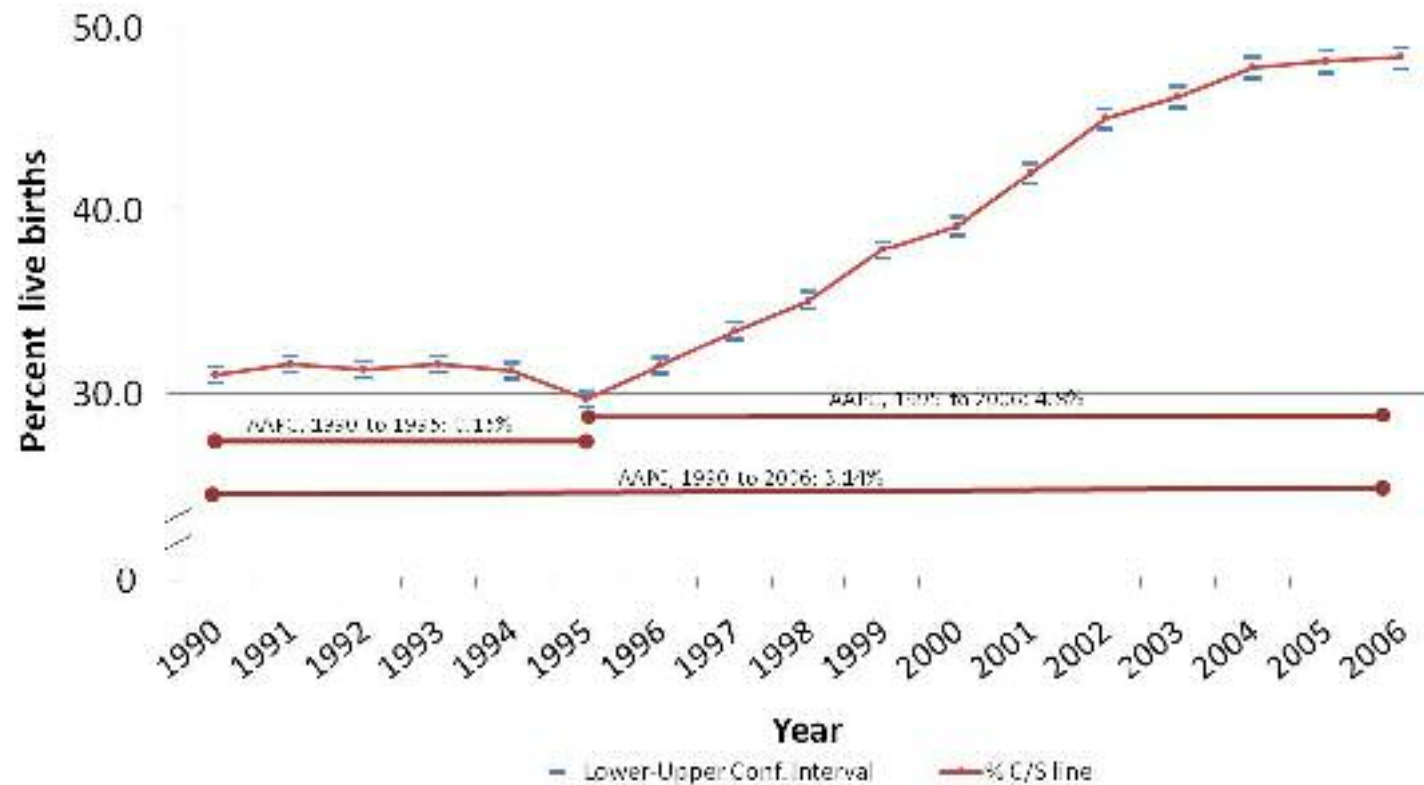


Source: Puerto Rico Department of Health, Vital Statistics Data 1990-2006.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-9

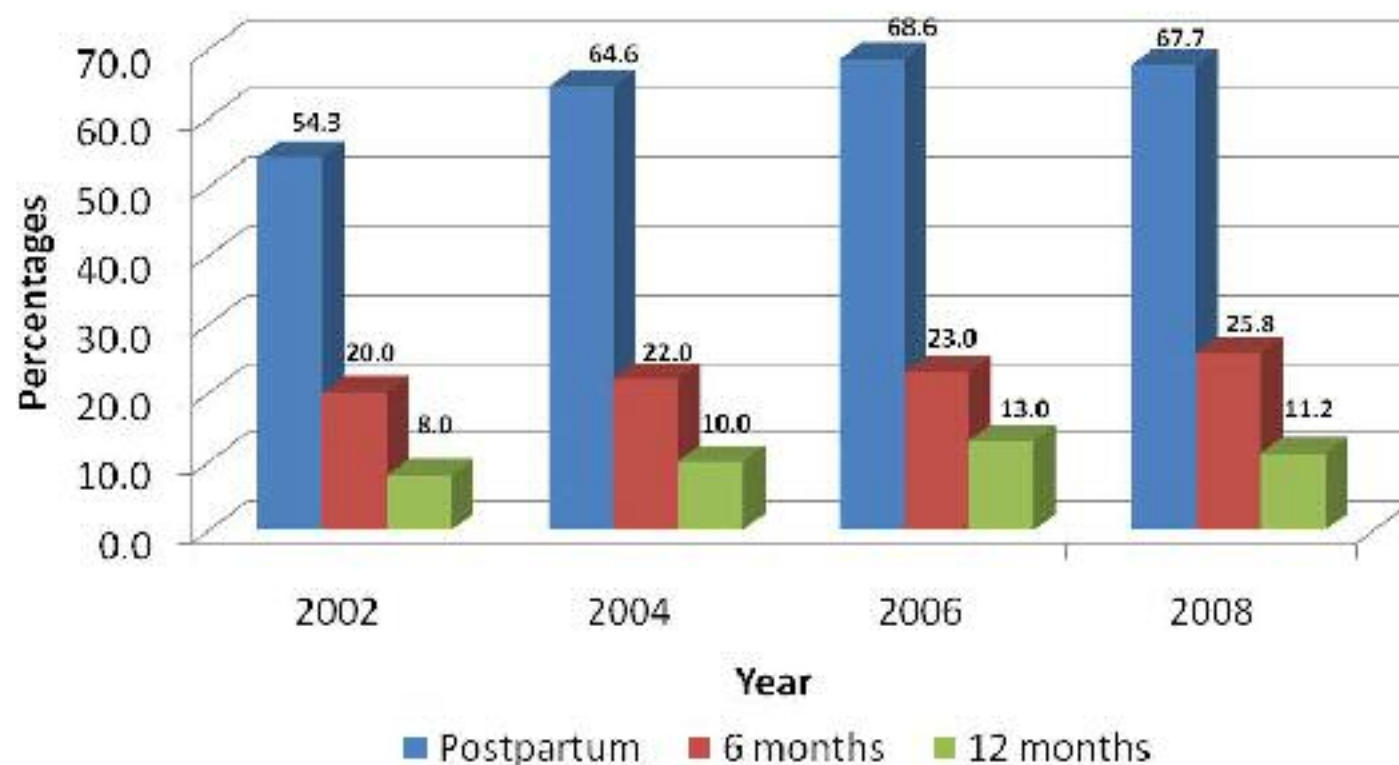
Percent of Cesarean Section Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Vital Statistics Data 1990-2006.
Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-10

Puerto Rico Maternal-Infant Health Survey (ESMIPR) Time of Breastfeeding



Source: ESMIPR 2000, 2002, 2004, 2006 and 2008.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-11

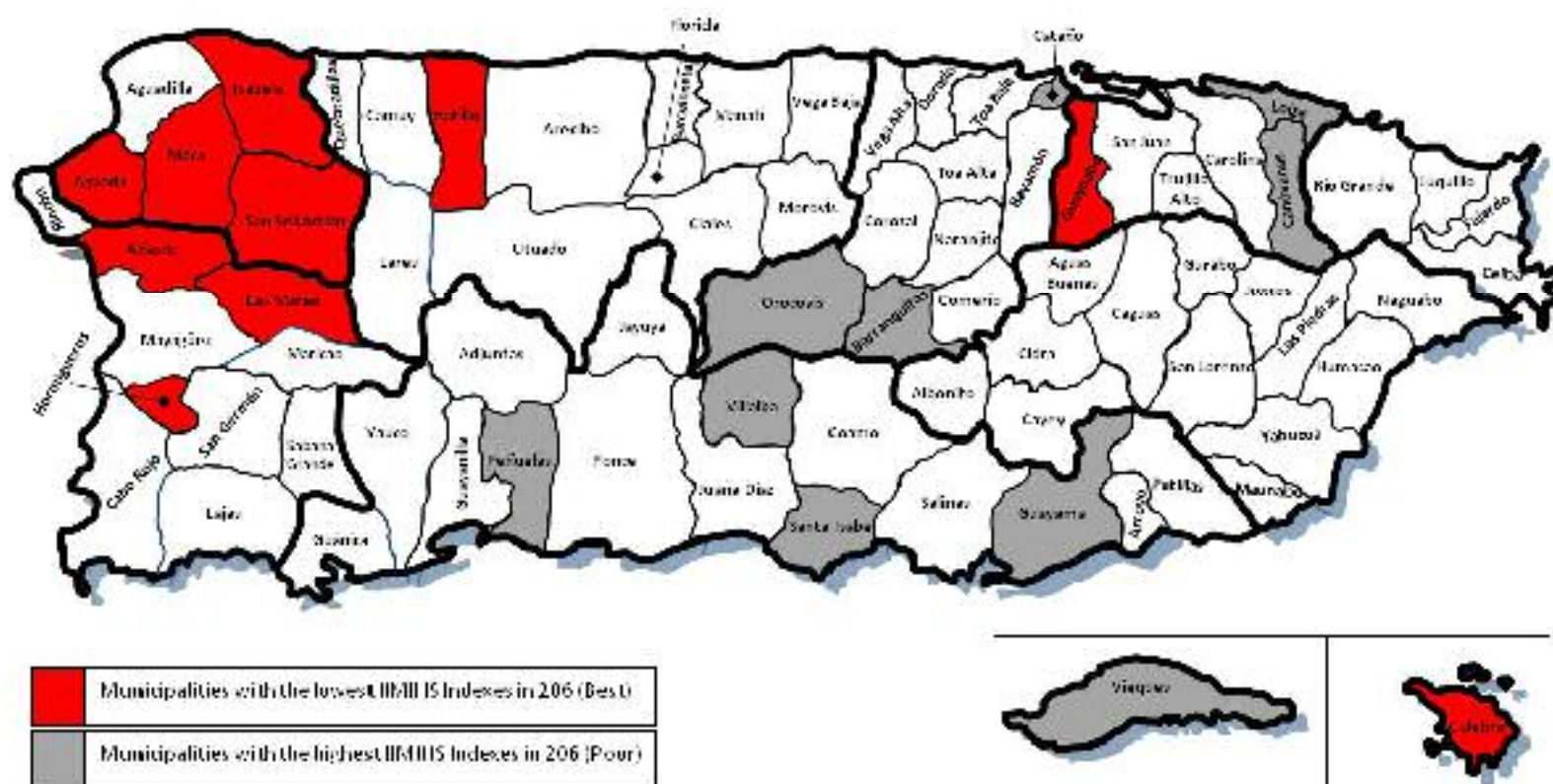
Municipalities with the highest and lowest IIMIHS Puerto Rico: 2006

The map displays the following municipalities categorized by their IIMIHS index:

- Lowest IIMIHS Index (Red):** Aguadilla, Aguas Buenas, Arecibo, Bayamón, Caguas, Camuy, Carolina, Guayama, Humacao, Mayaguez, Ponce, San Juan, San Lorenzo, San Sebastián, Vega Baja, Yabucoa.
- Highest IIMIHS Index (Gray):** Aguas Buenas, Arecibo, Bayamón, Caguas, Camuy, Carolina, Guayama, Humacao, Mayaguez, Ponce, San Juan, San Lorenzo, San Sebastián, Vega Baja, Yabucoa.

Source: Puerto Rico Department of Health, Division of Maternal Health, IIMIHS 2006.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

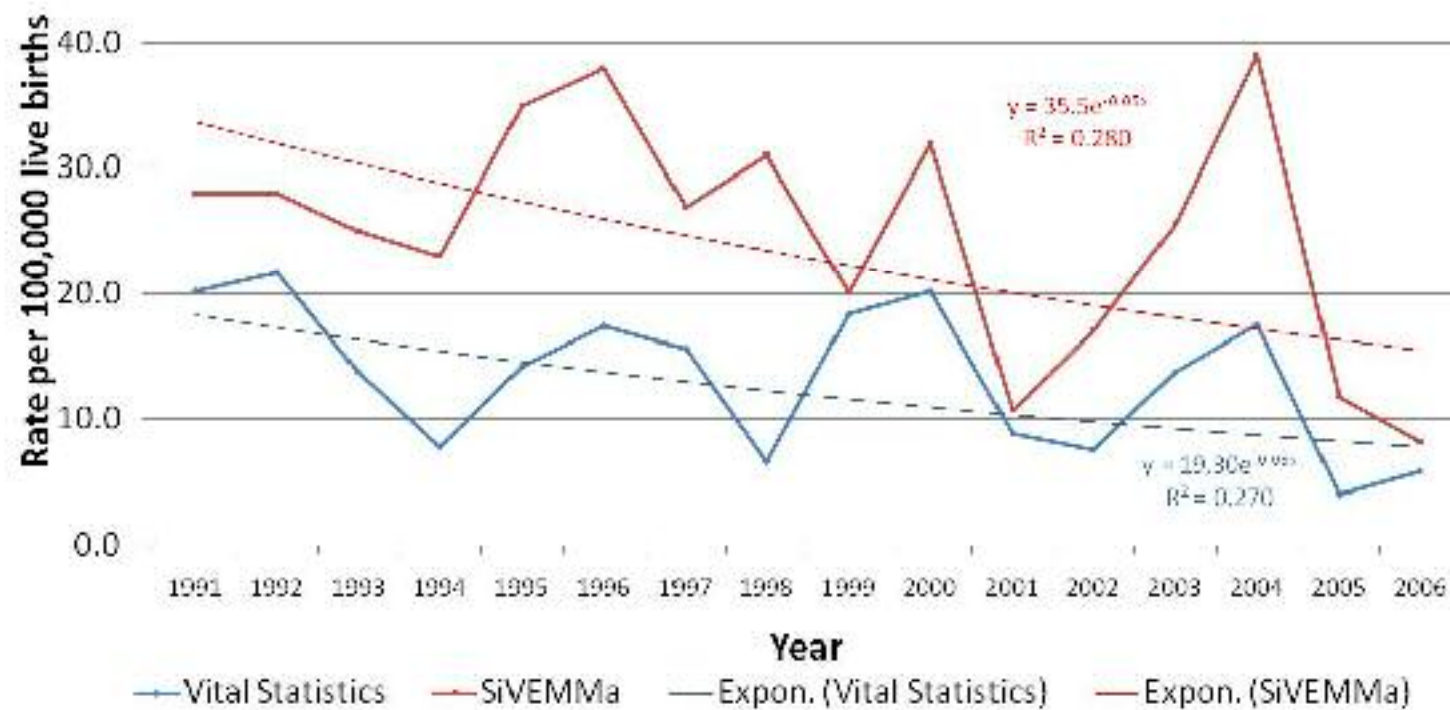
Municipalities with the highest and lowest IIMIHS
Puerto Rico: 2006



Source: Puerto Rico Department of Health, Division of Maternal Health, DMHS 2006.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-12

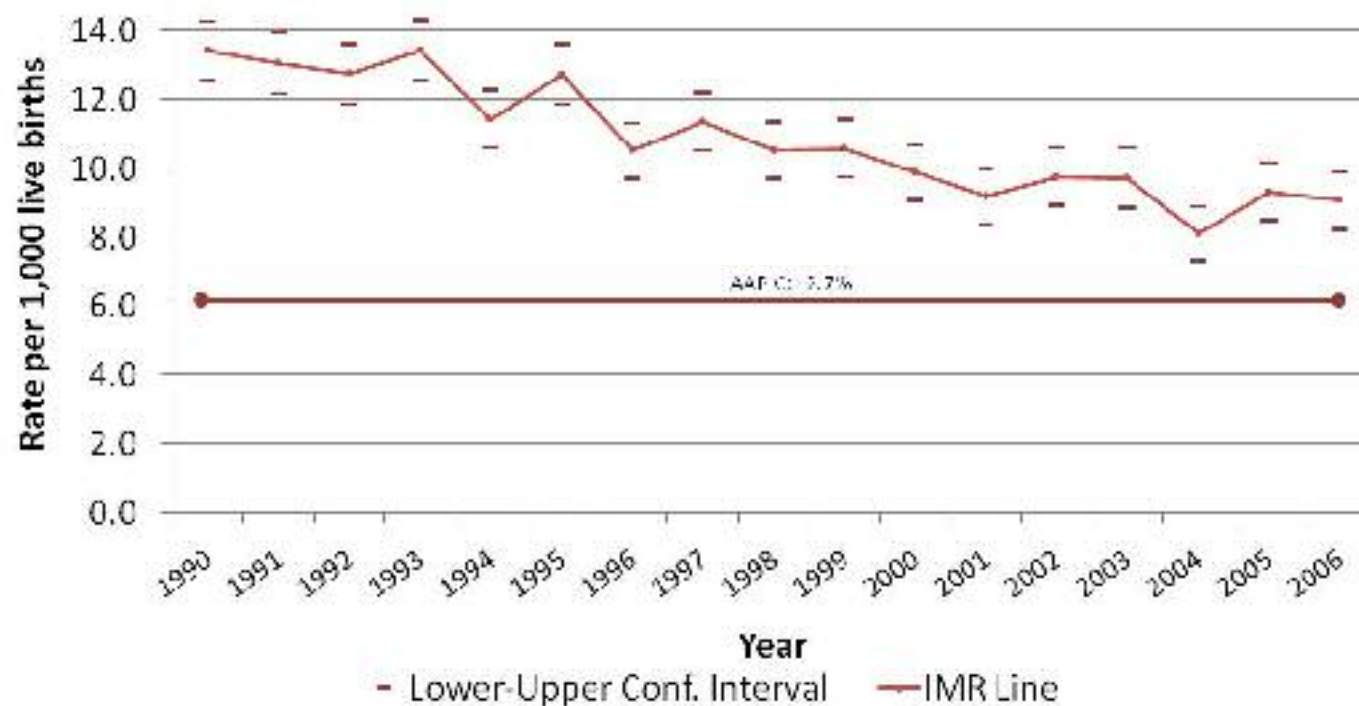
Pregnancy related deaths: Vital Statistics vs. SiVEMMAa Puerto Rico: 1991-2006



Source: Puerto Rico Department of Health, Division of Maternal Health;
Puerto Rico Epidemiologic Survey System.
Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-13

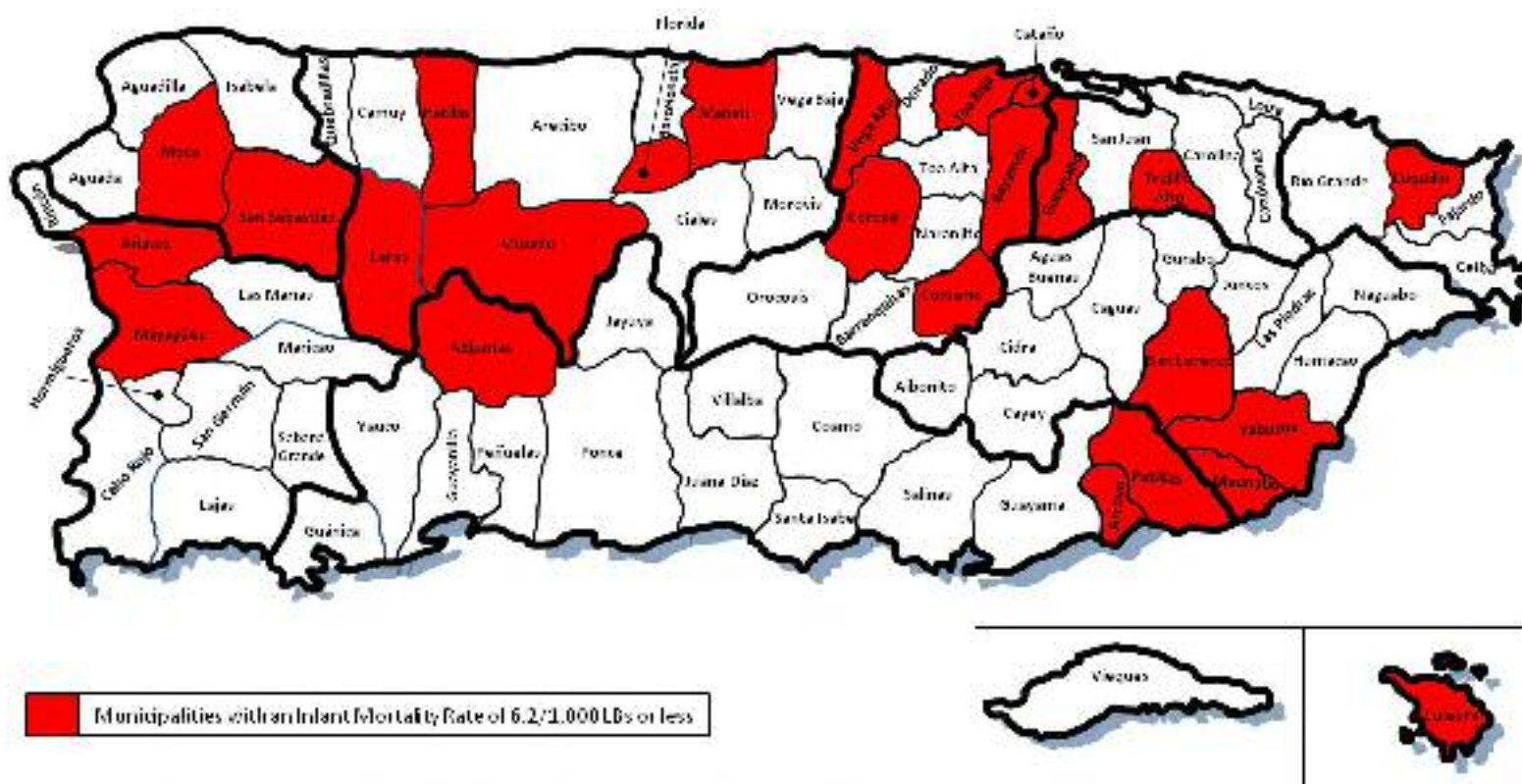
Infant Mortality Rates Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-14

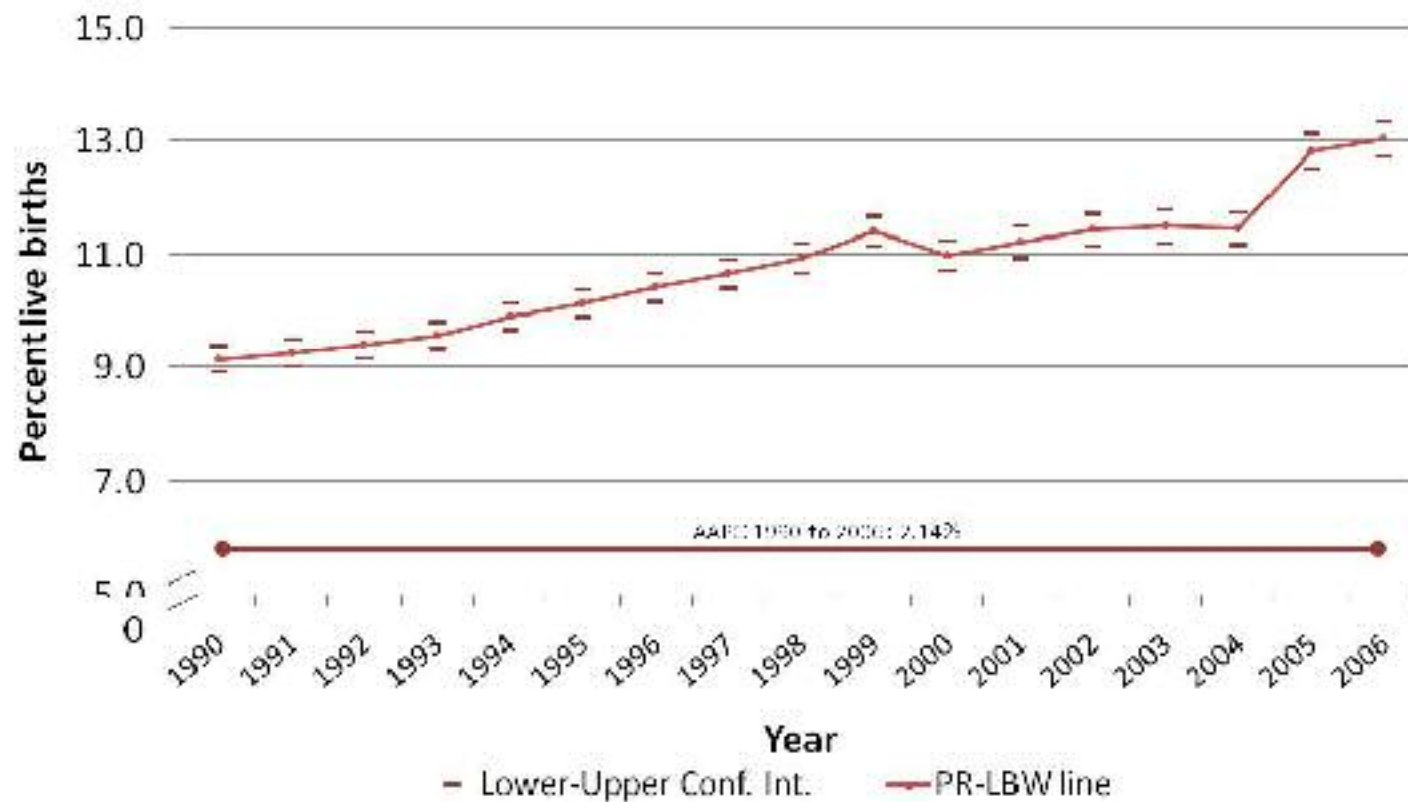
Municipalities with an Infant Mortality Rate of 6.2/1,000 LBs or less
Puerto Rico: 2006



Source: Puerto Rico Department of Health, Division of Maternal Health, IIM HS 2006.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health

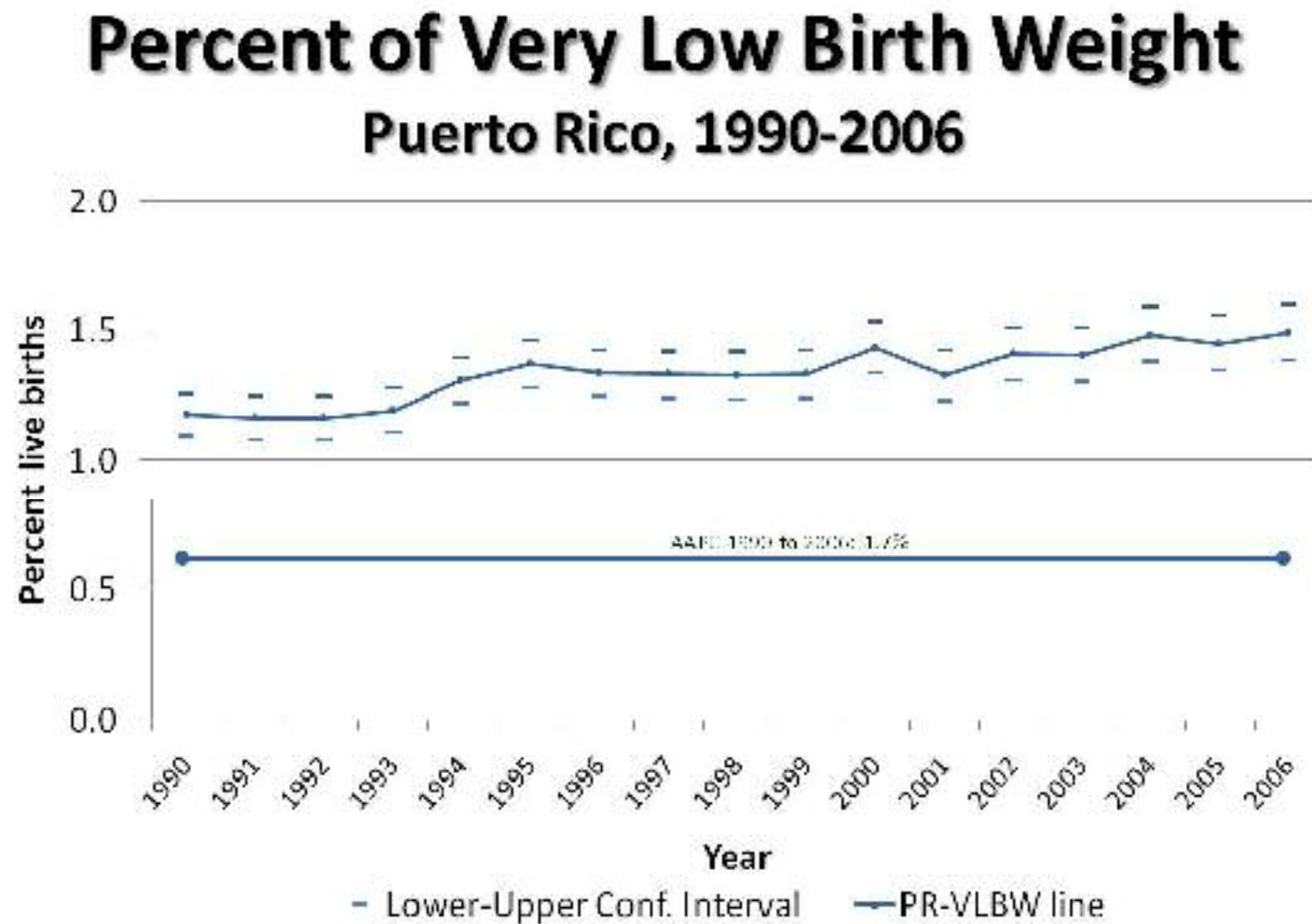
Figure II-15

Percent of Low Birth Weight Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

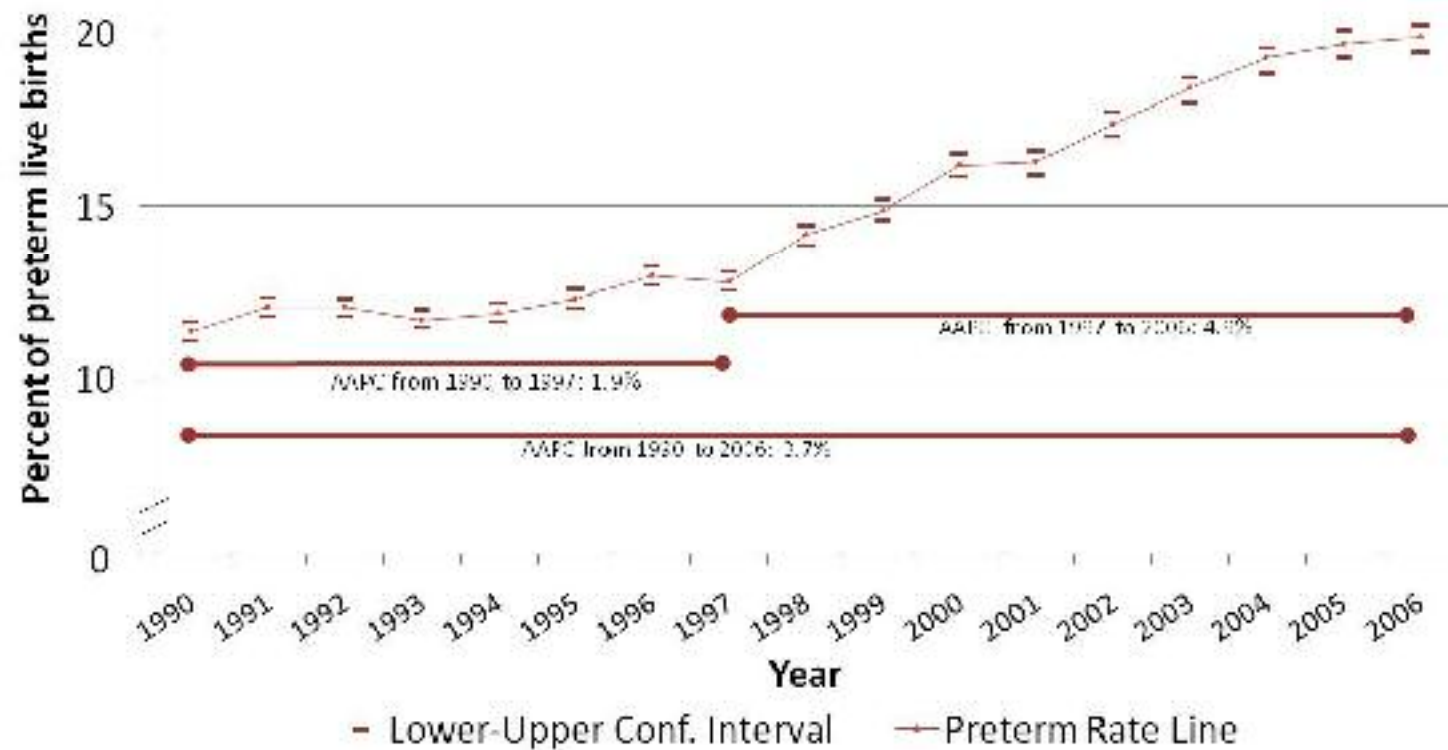
Figure II-16



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-17

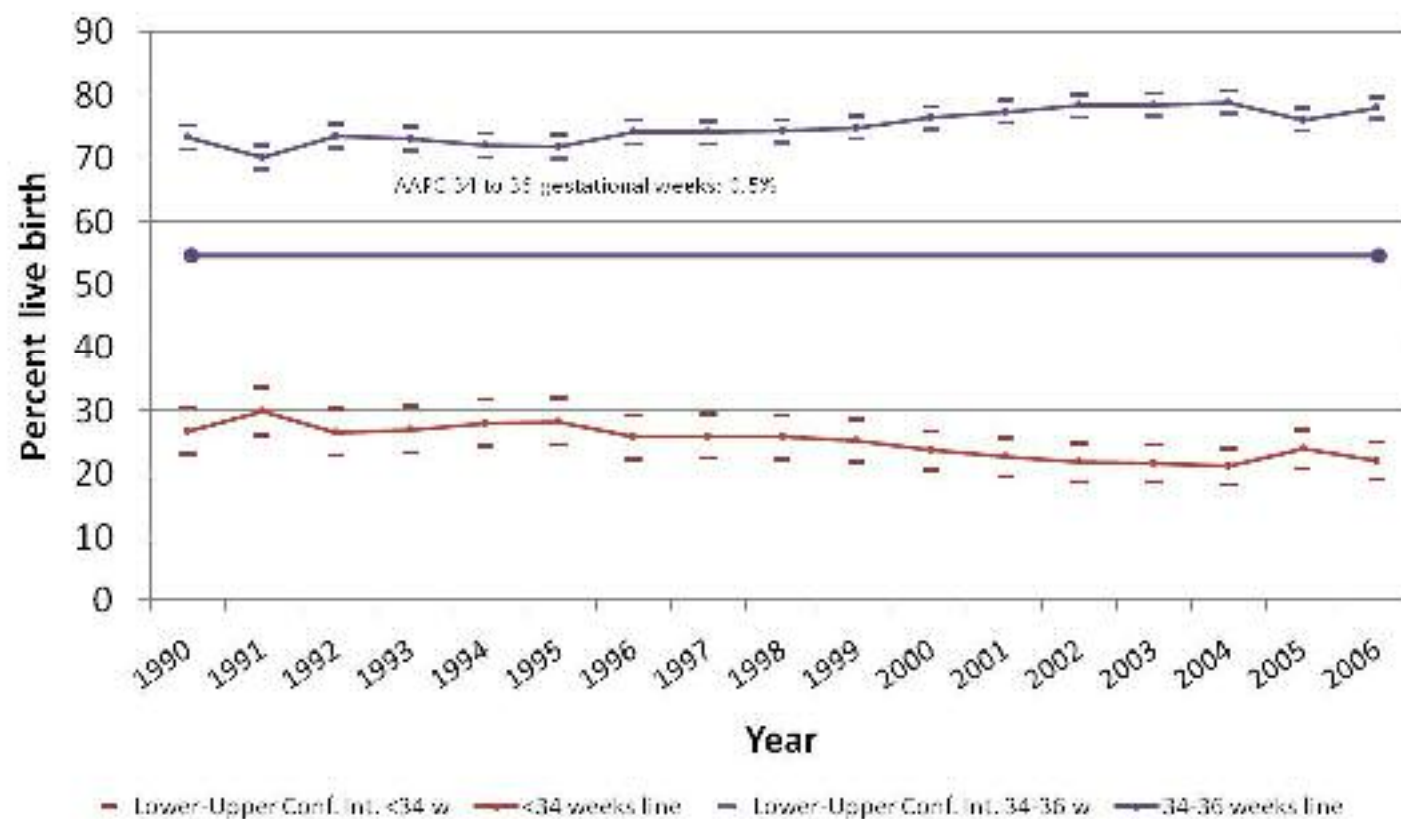
Percent of Preterm Births Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-18

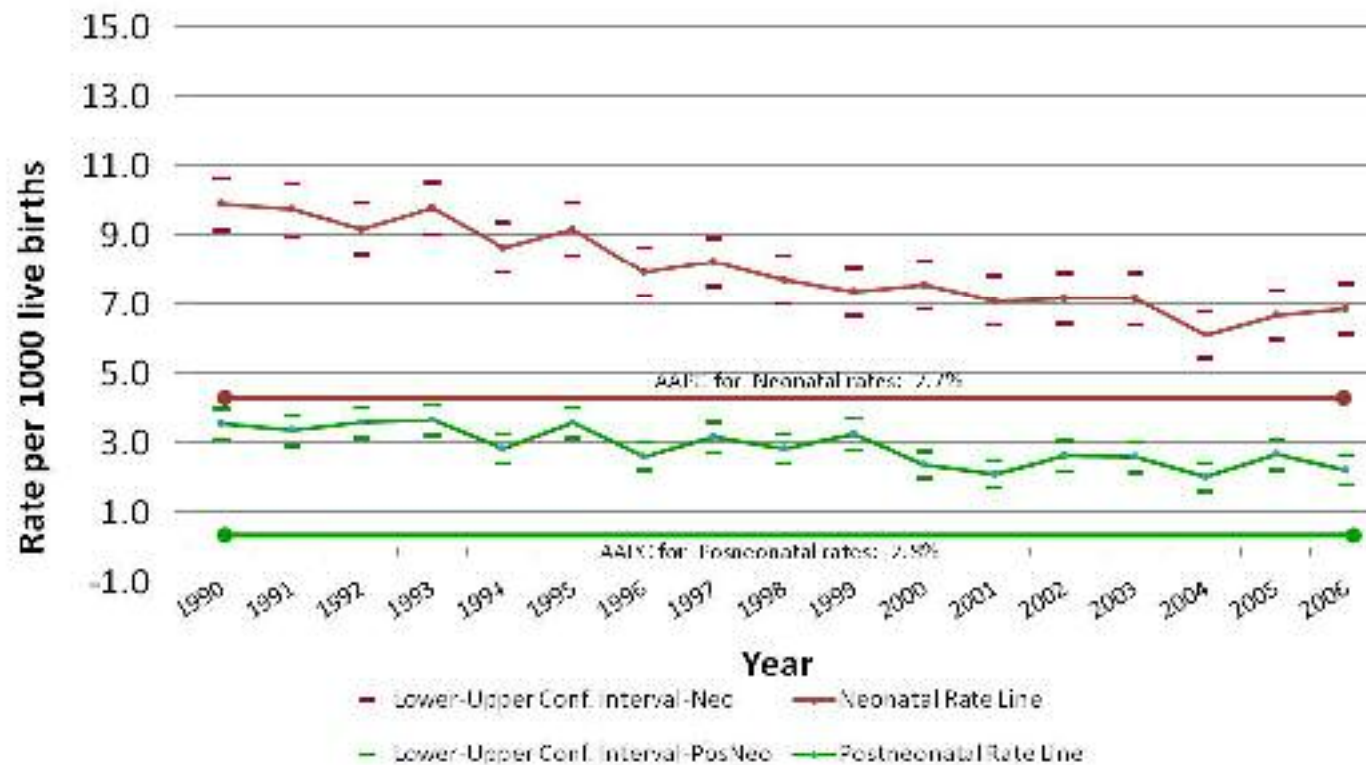
Percent of Early & late Preterm Births Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-19

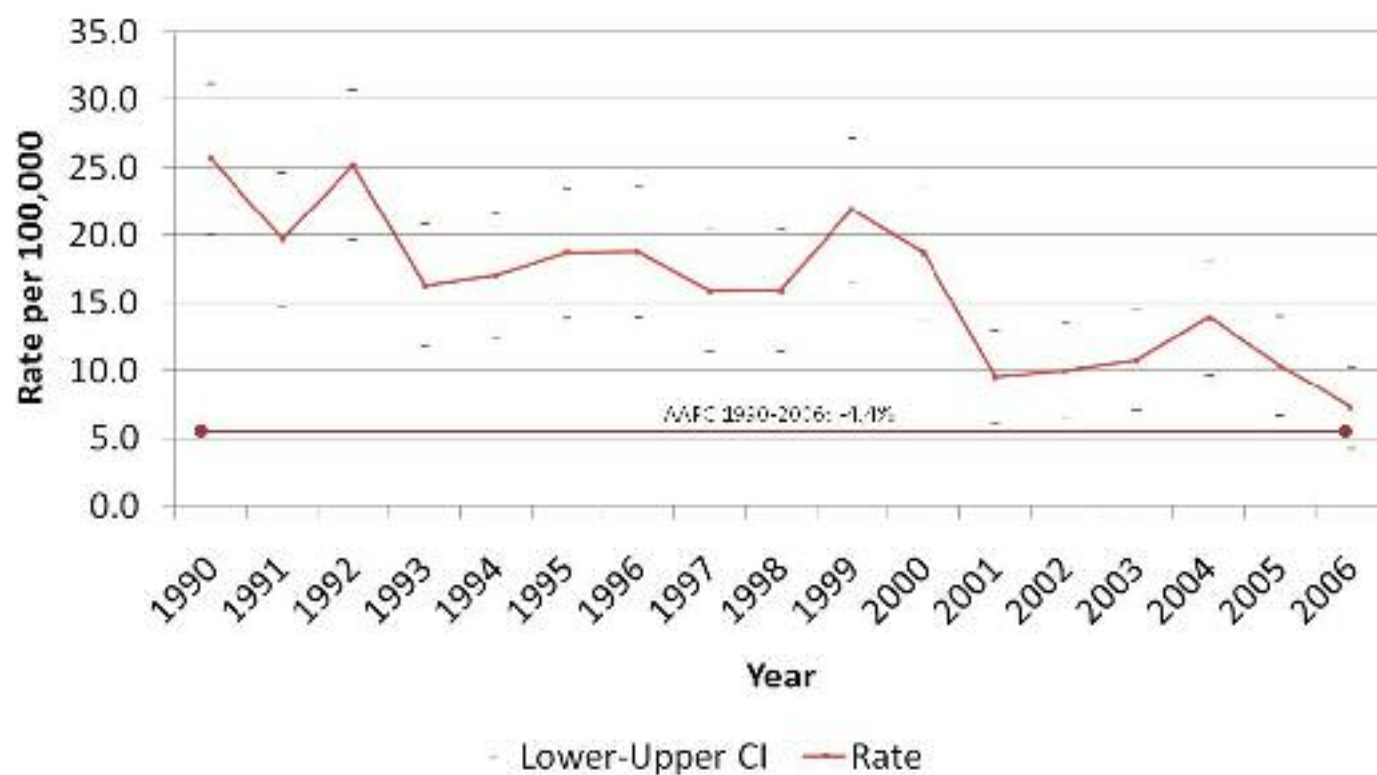
Neonatal & Postneonatal Mortality Rates Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Division of Maternal Health.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-20

Pediatric Mortality Rates 5-9 Years Old Puerto Rico: 1990 to 2006

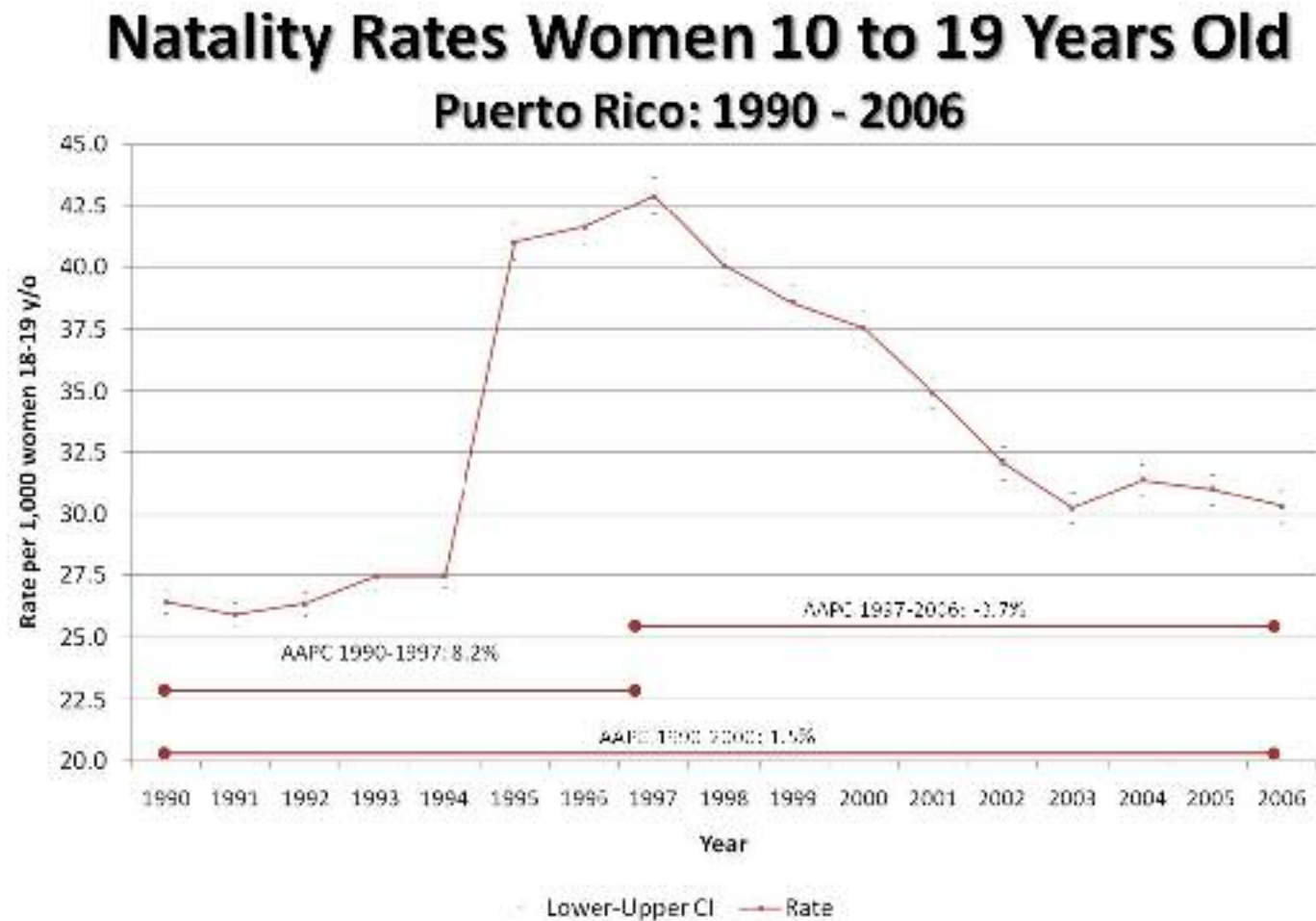


Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-21



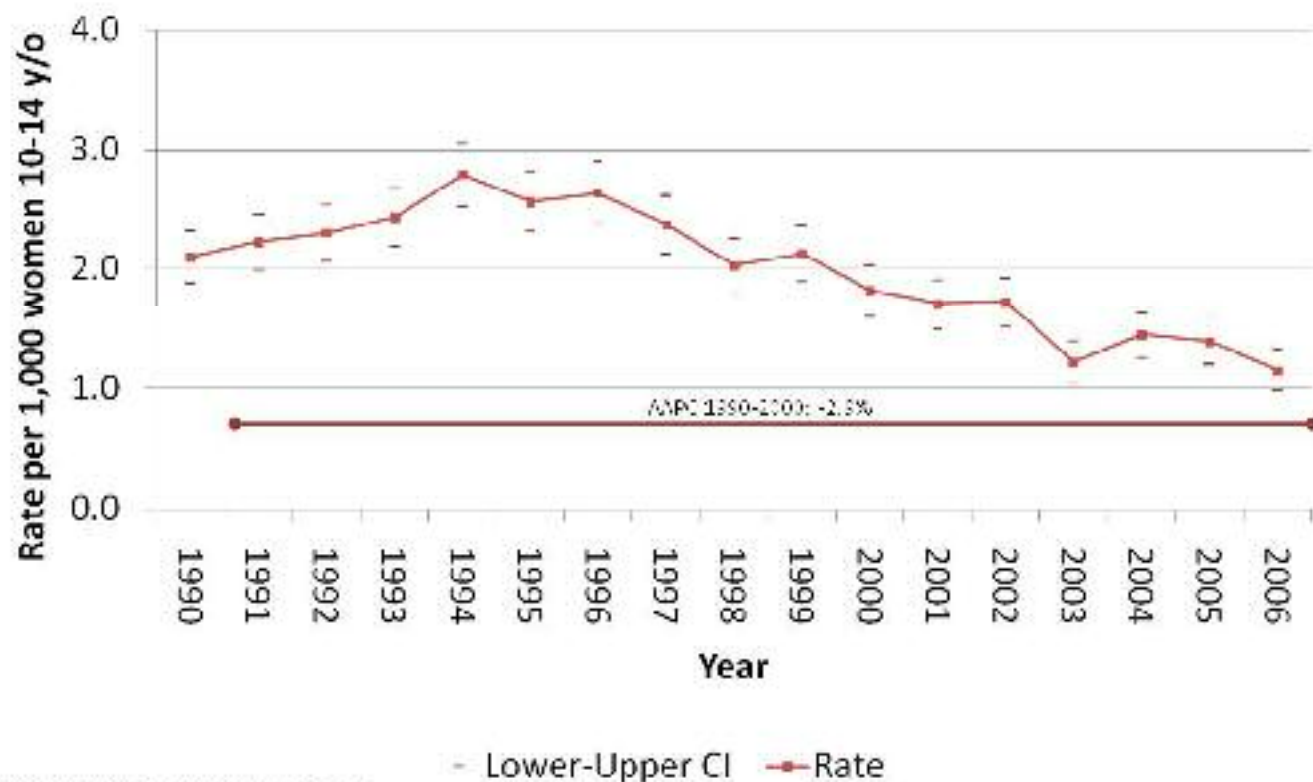
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-22

Nativity Rates Women 10 to 14 Years Old Puerto Rico: 1990 - 2006



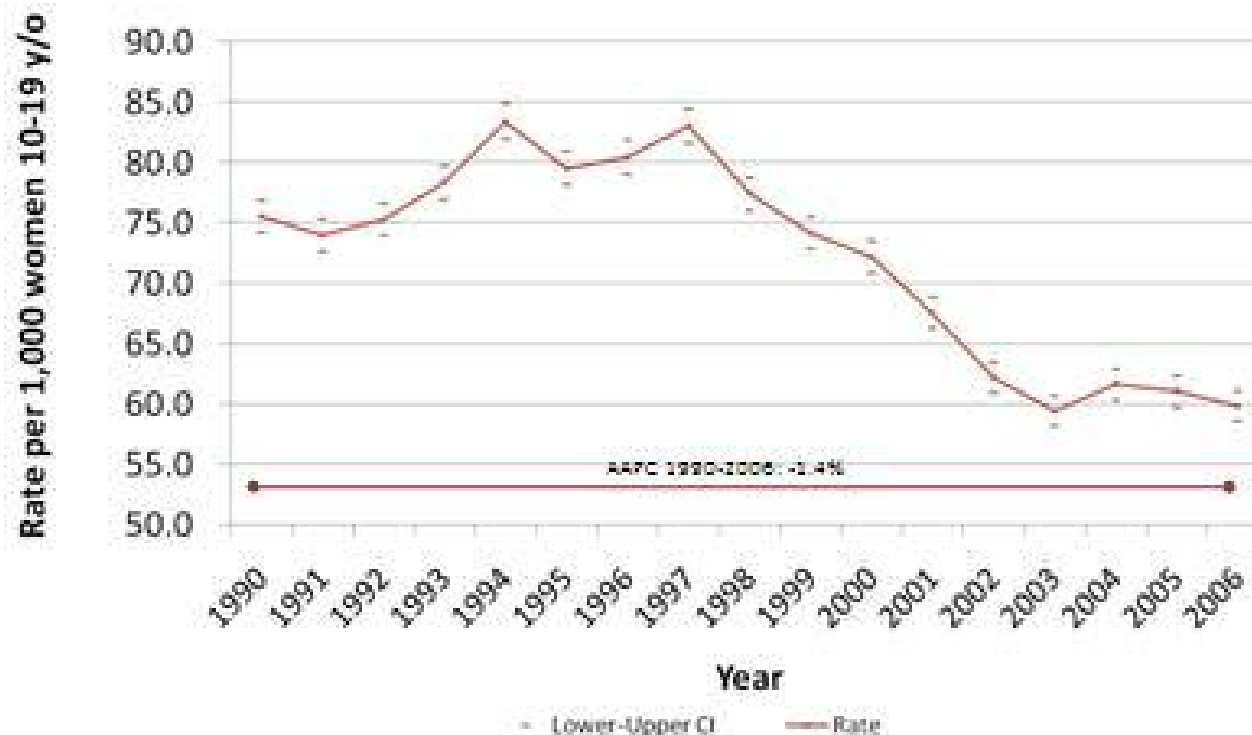
Source: PR Planning Board, Census Office

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-23

Natality Rates Women 15 to 19 Years Old Puerto Rico: 1990 - 2006



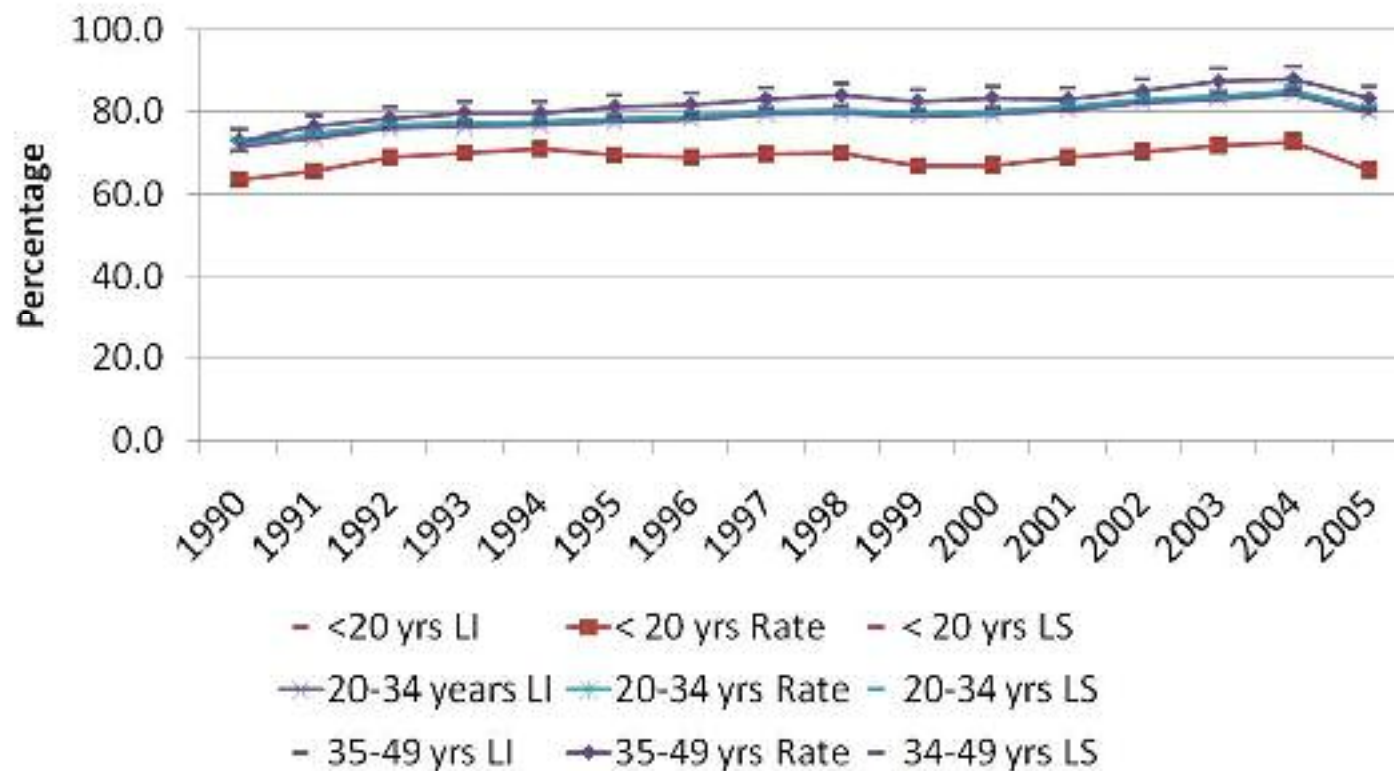
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-24

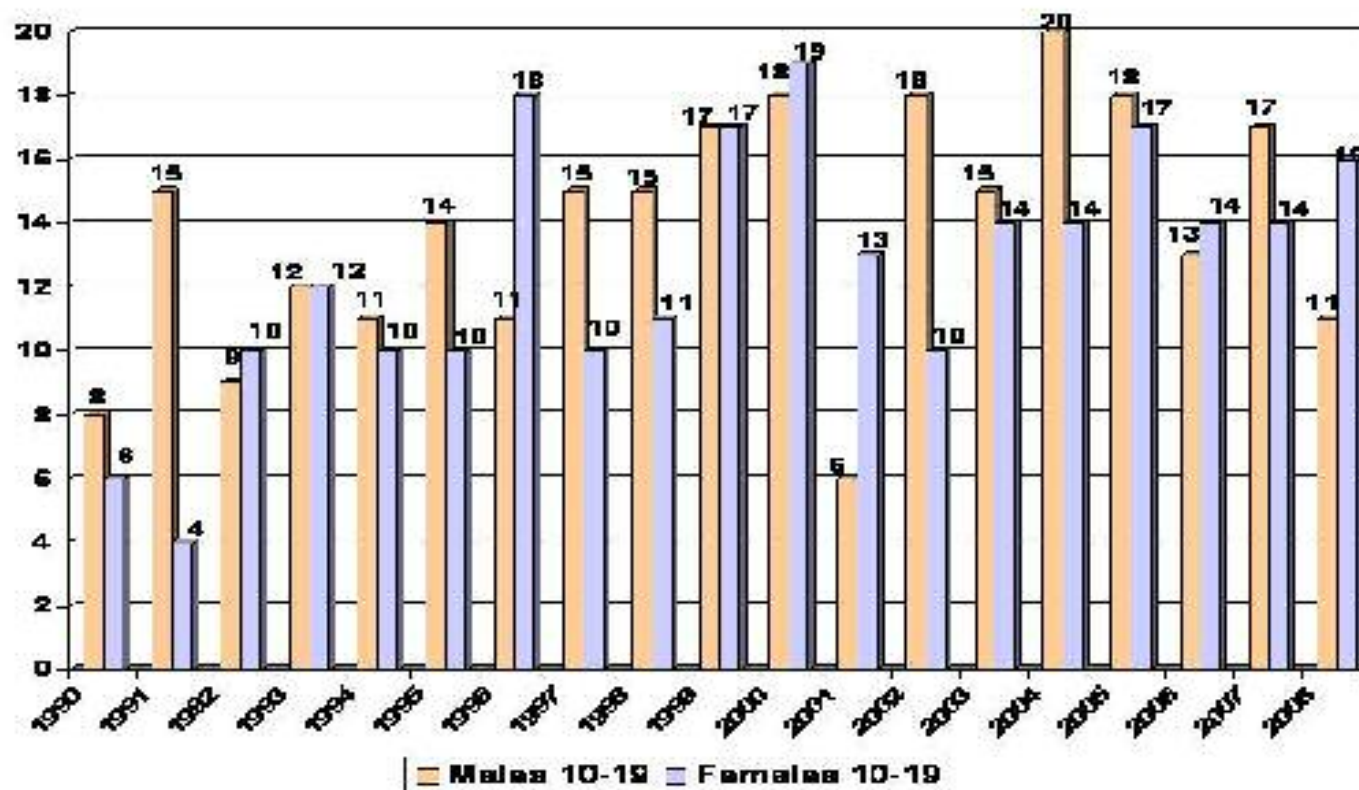
Prenatal Care 1st Trimester by Maternal Age Puerto Rico: 1990-2006



Source: Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.
Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II - 25

HIV/AIDS Cases by Sex Puerto Rico: 1990-2008

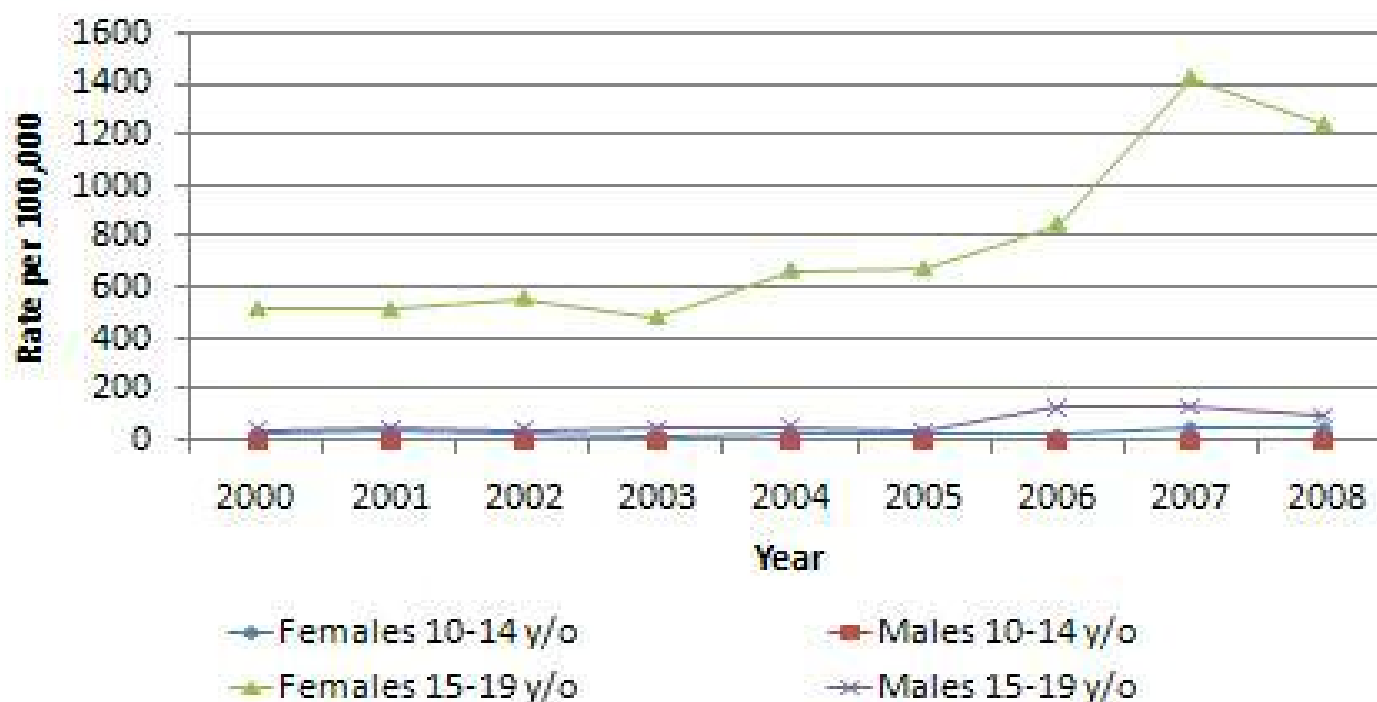


Source: PR Department of Health, HIV/AIDS Surveillance System.

Prepared: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-26

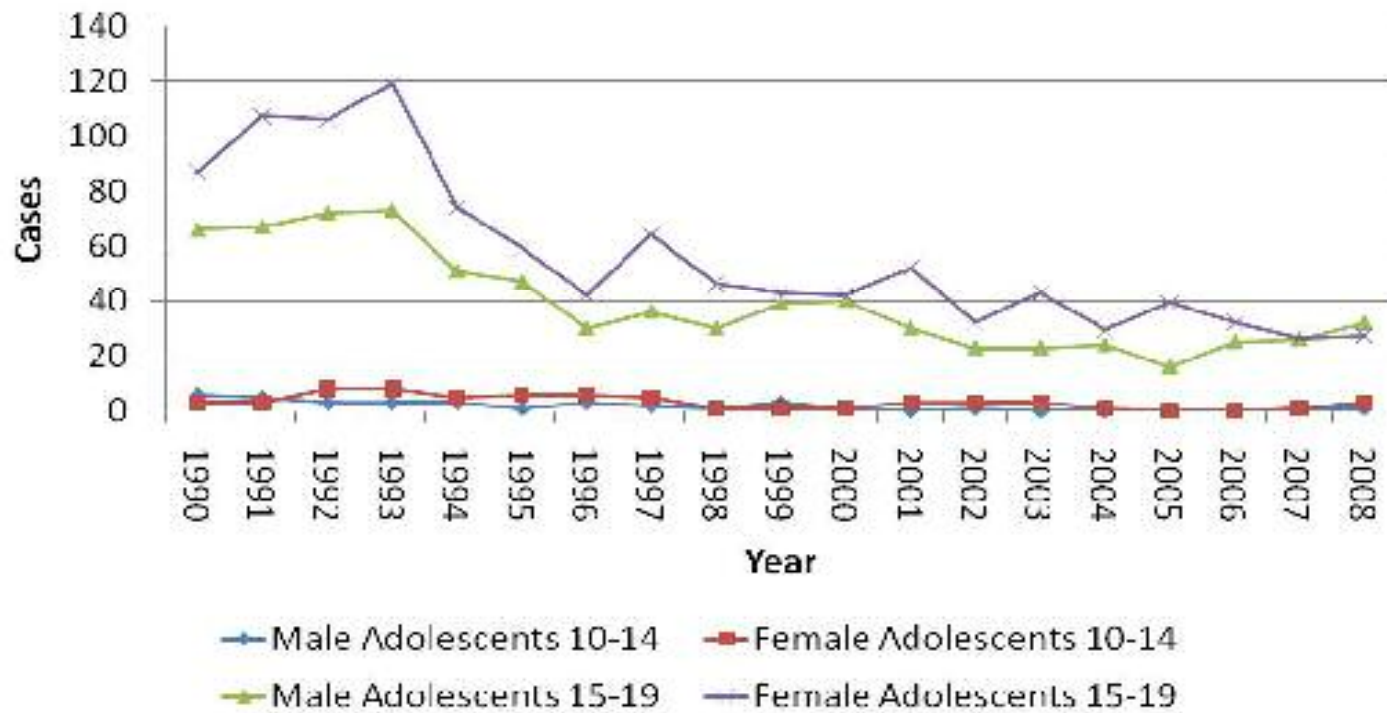
Rates of Chlamydial Infections among Adolescents Puerto Rico: 2000-2008



Source: Puerto Rico Department of Health; STD/HIV Prevention Program, Surveillance Office.
Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-27

Trends in Syphilis Infections among Adolescents by Age Group and Sex Puerto Rico: 1990-2008

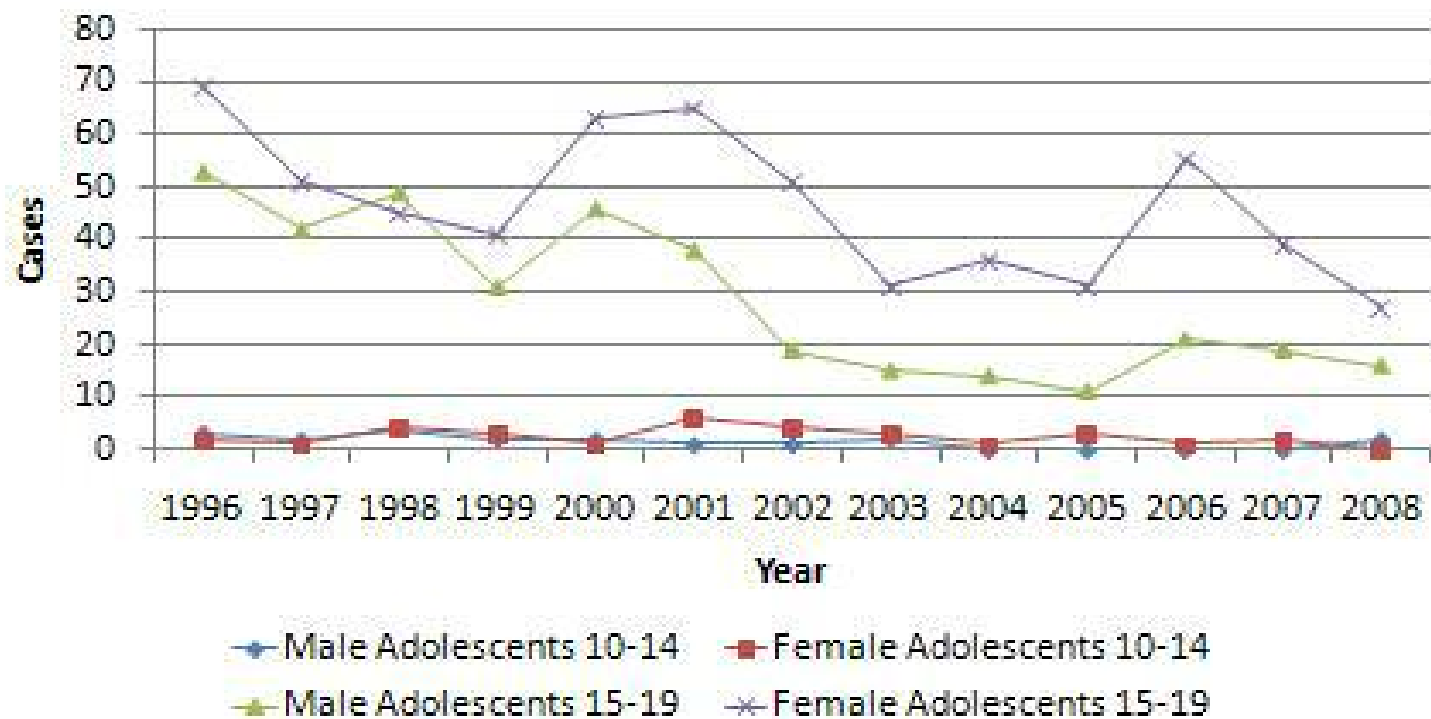


Source: Puerto Rico Department of Health; STD Surveillance System.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-28

Trends in Gonorrhea Infections among Adolescents by Age Group and Sex Puerto Rico: 1990-2008

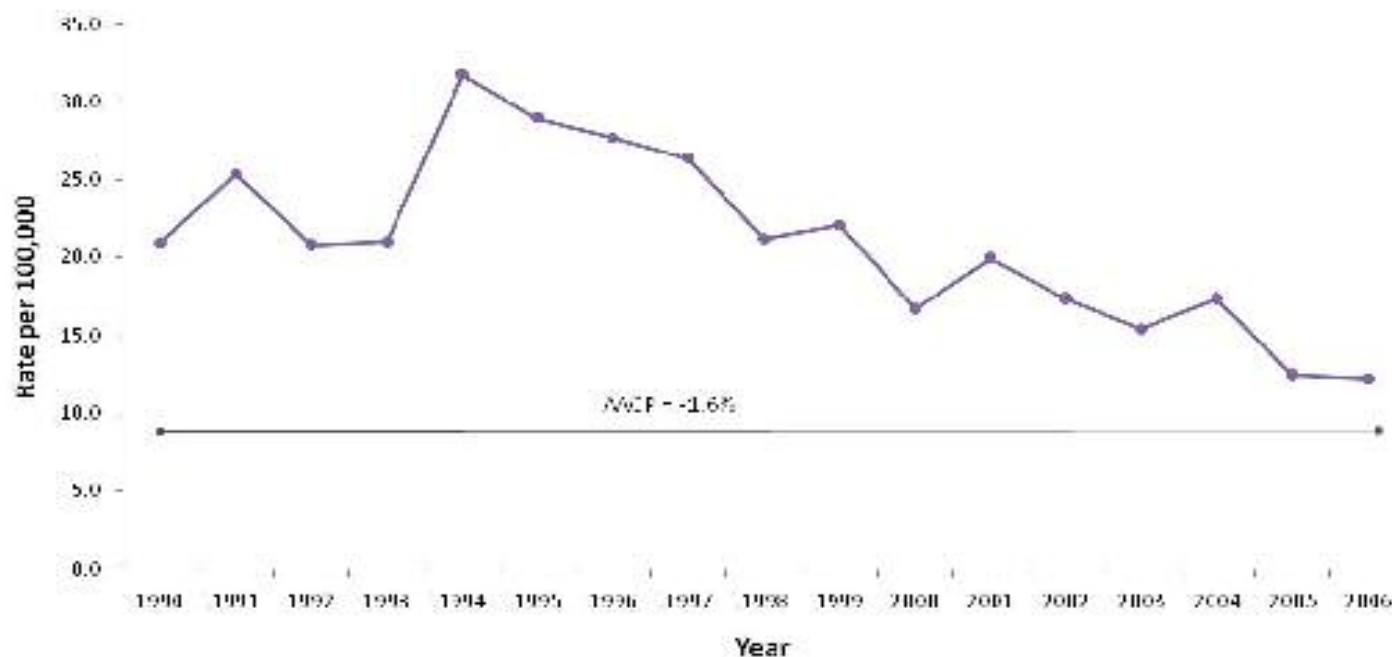


Source: Puerto Rico Department of Health; STD Surveillance System.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-29

Adolescent Mortality Rates 10 to 14 Years Old: Puerto Rico: 1990 to 2006



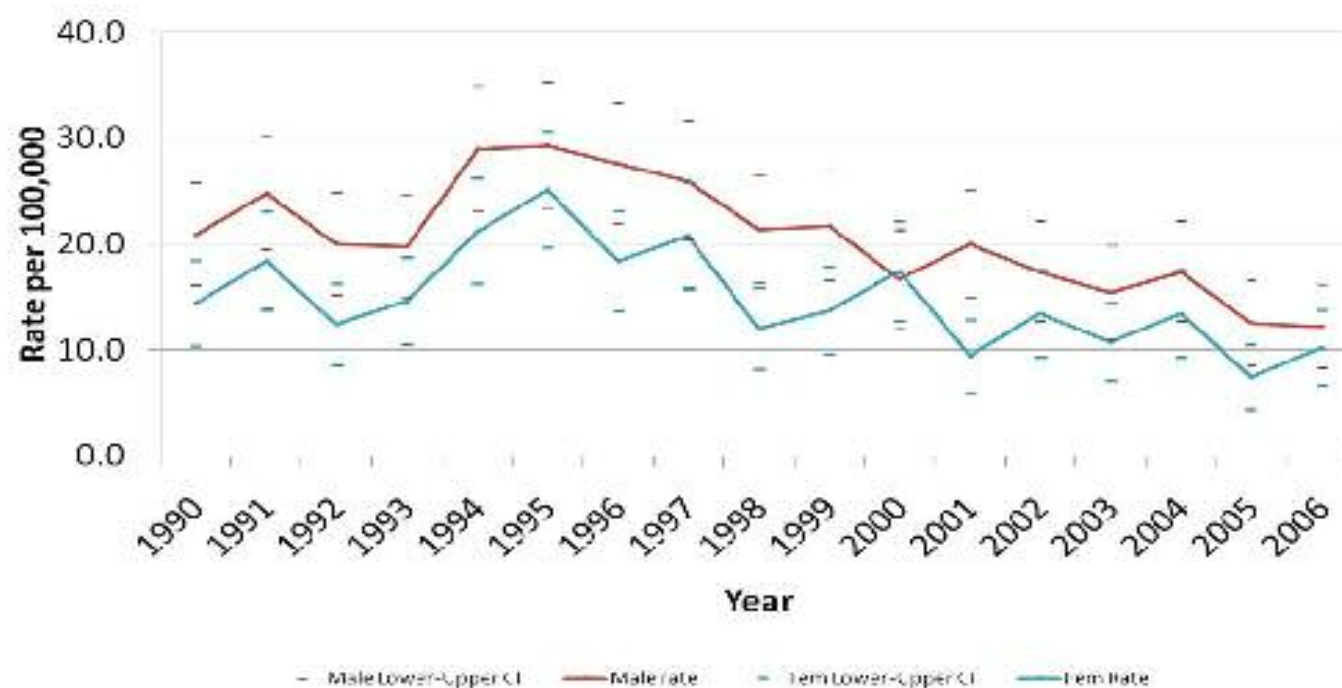
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-30

Adolescent Mortality Rates 10 to 14 Years Old by Sex Puerto Rico: 1990 to 2006



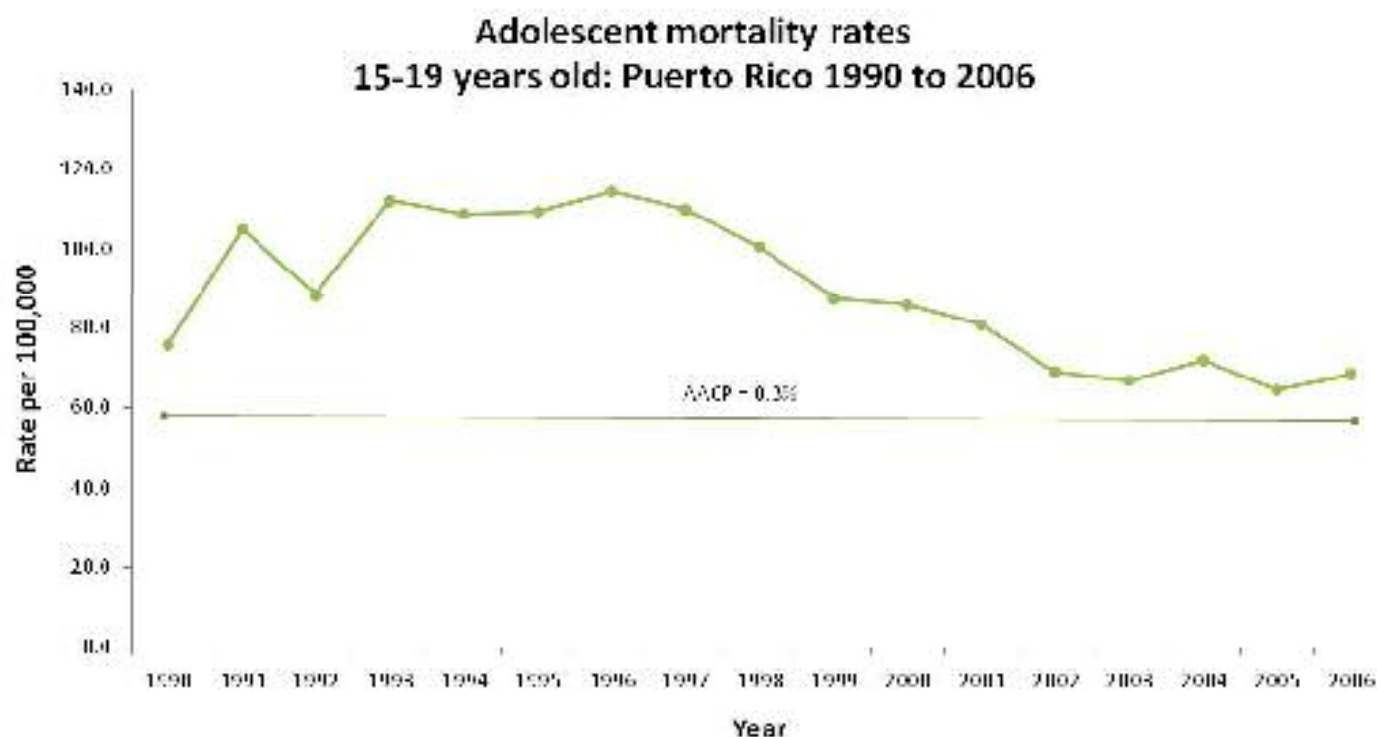
Source: PR Planning Board, Census Office.

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-31

Adolescent Mortality Rates 15 to 19 Years Old Puerto Rico: 1990 to 2006



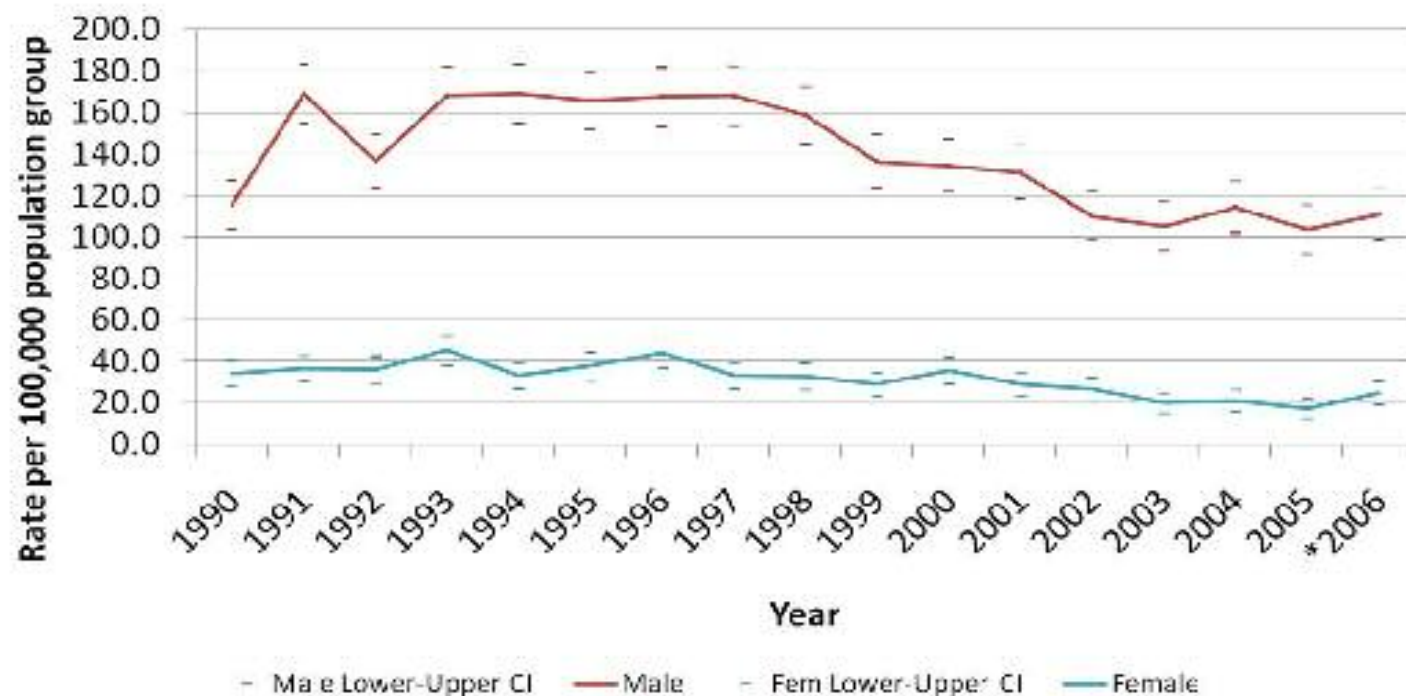
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-32

Adolescent Mortality Rates 15 to 19 Years Old by Sex Puerto Rico: 1990 to 2006



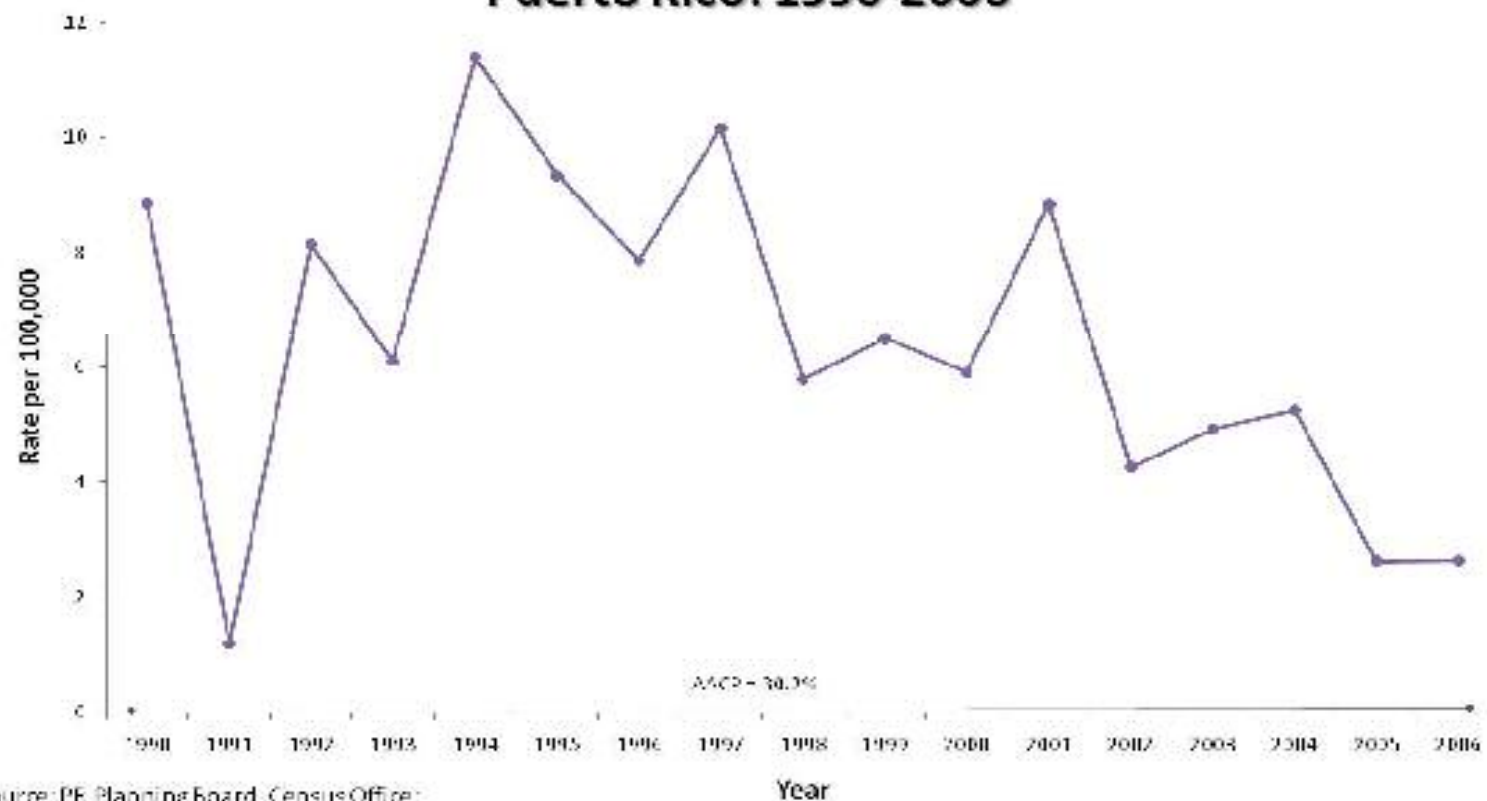
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-33

Unintentional Injuries Mortality Rates Population 10-14 Years Old Puerto Rico: 1990-2006



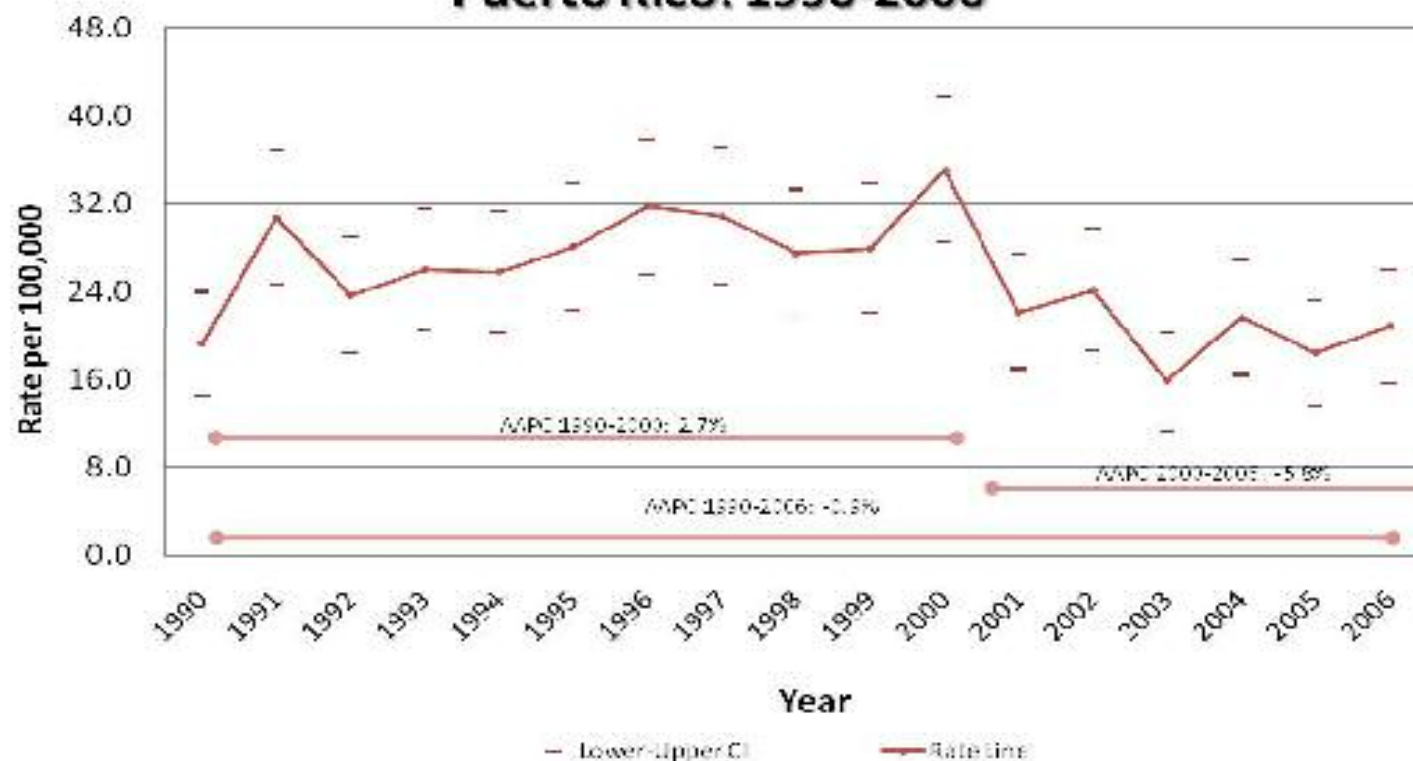
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-34

Unintentional Injuries Mortality Rates in Adolescents 15 to 19 Years Old Puerto Rico: 1990-2006



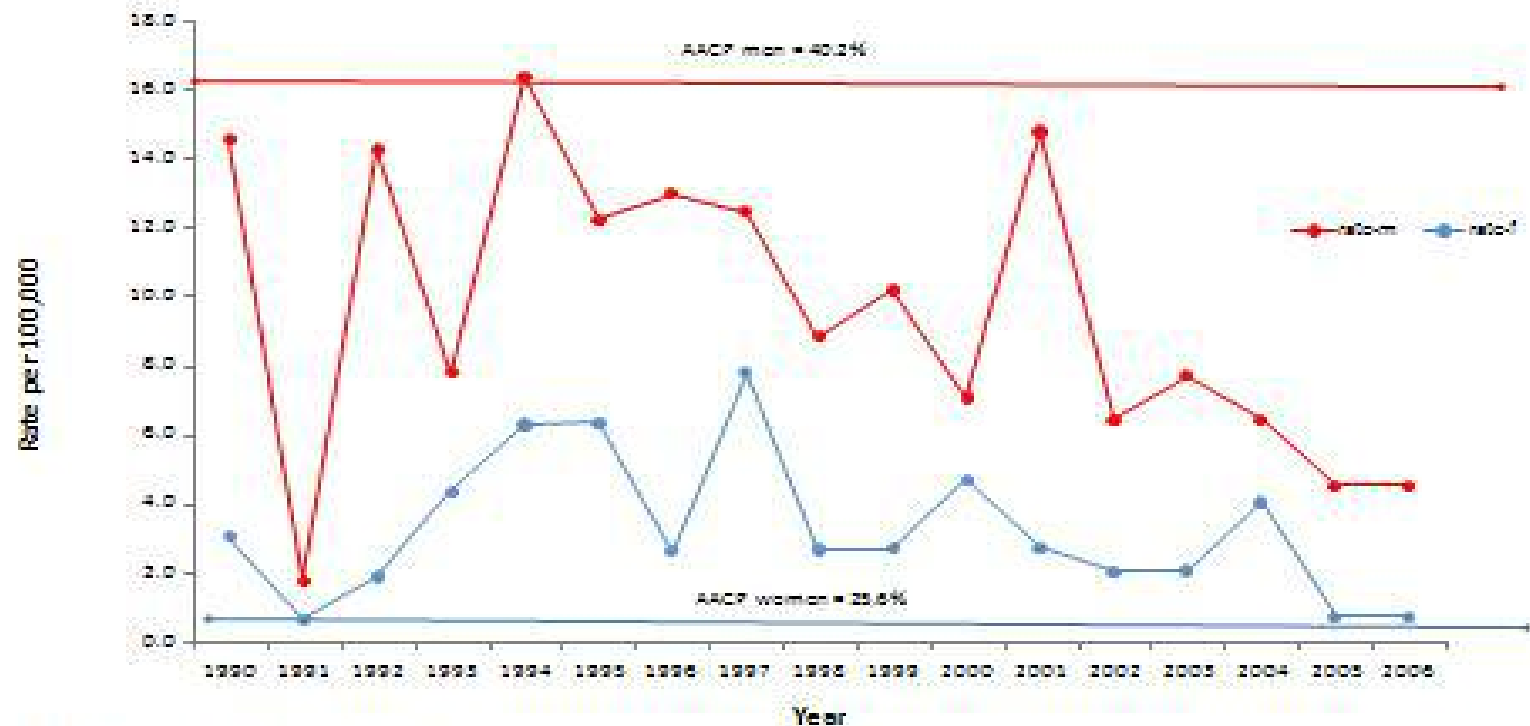
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-35

Unintentional Injuries Rates in Adolescents 10 to 14 Years Old by Sex Puerto Rico: 1990-2006



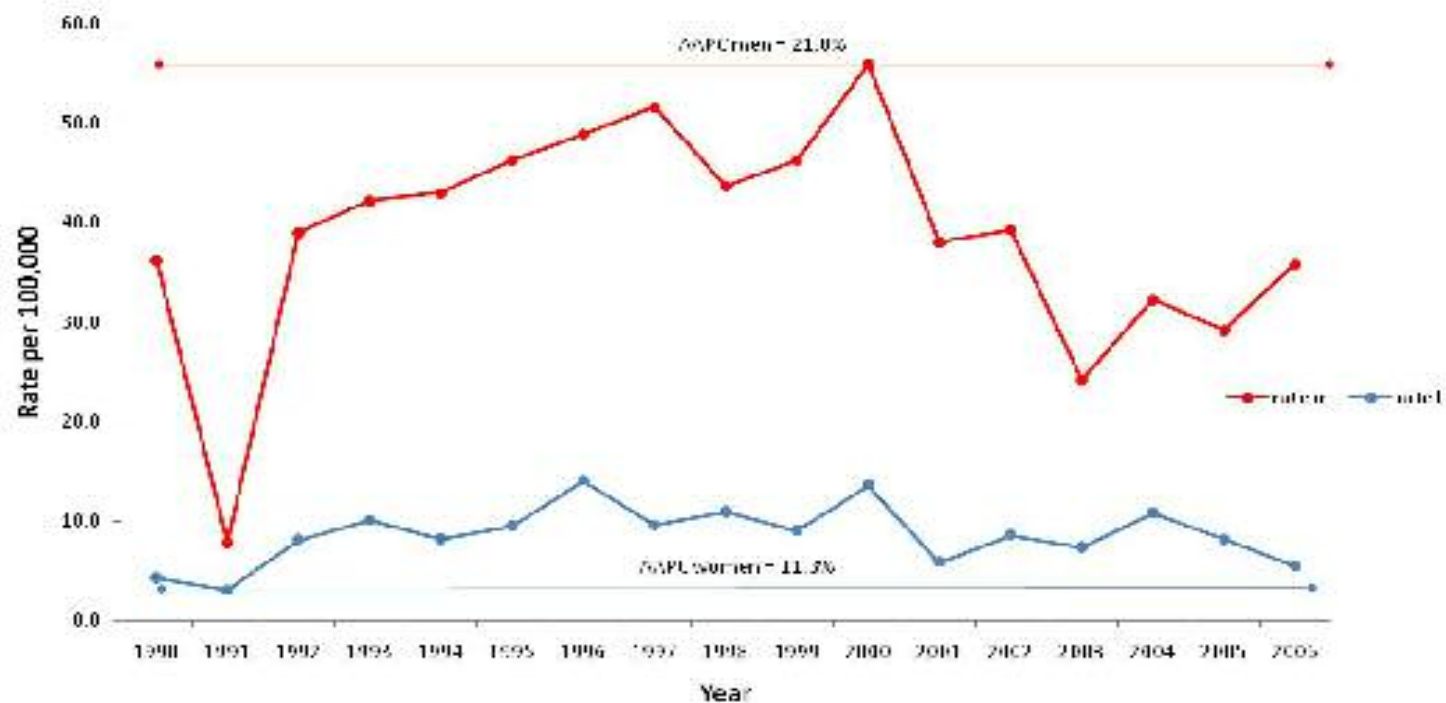
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2005, San Juan Puerto Rico.

Prepared by: Monitoring and Evaluation Section, Division of Maternal and Child Health.

Figure II-36

Unintentional Injuries Rates in Adolescents 15 to 19 Years Old by Sex Puerto Rico: 1990-2006



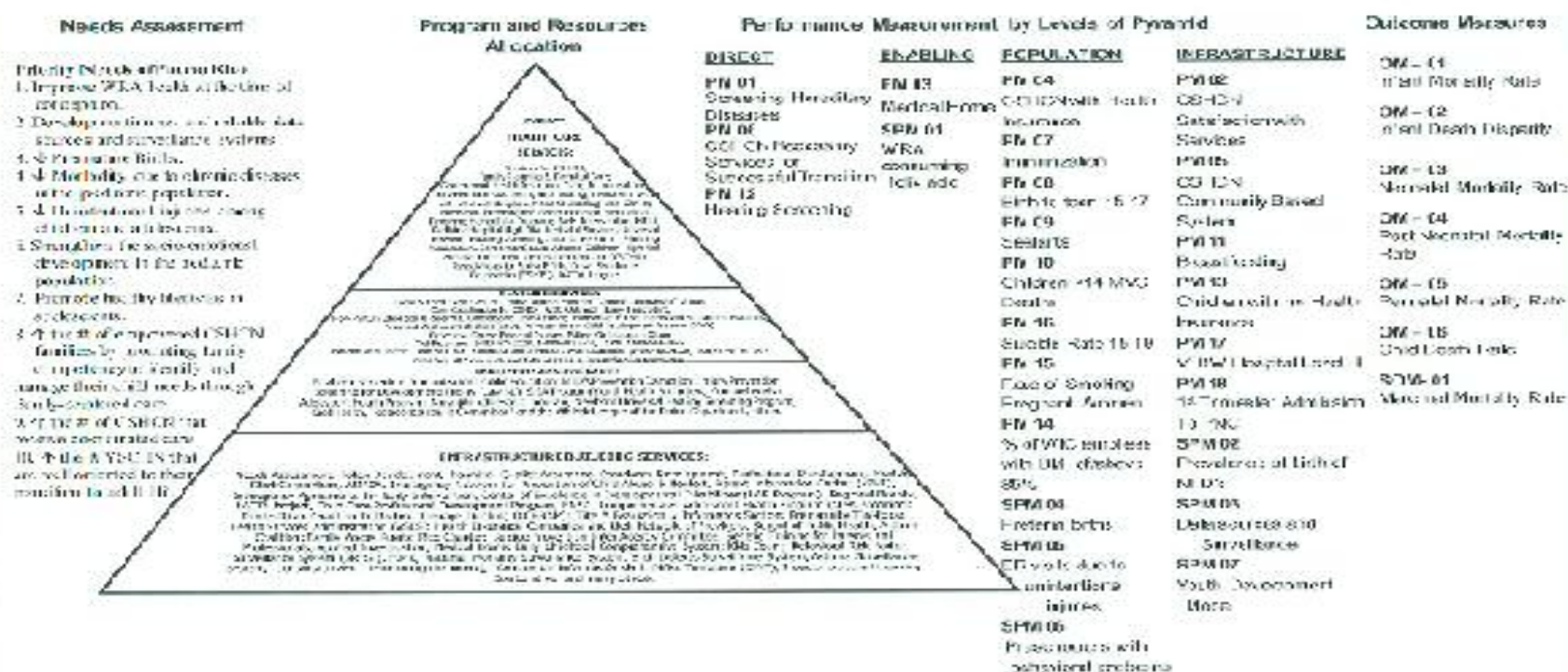
Source: PR Planning Board, Census Office;

Puerto Rico Department of Health, Vital Statistics Data 1990-2006, San Juan, Puerto Rico.

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-37

Puerto Rico Title V Block Grant Performance Measurement System



Health Insurance Administration Regions
Puerto Rico: 2010

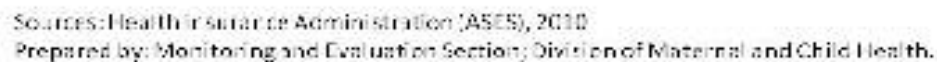


Figure II-39

Geographical Distribution of Nonprofit Organizations Puerto Rico: 2007

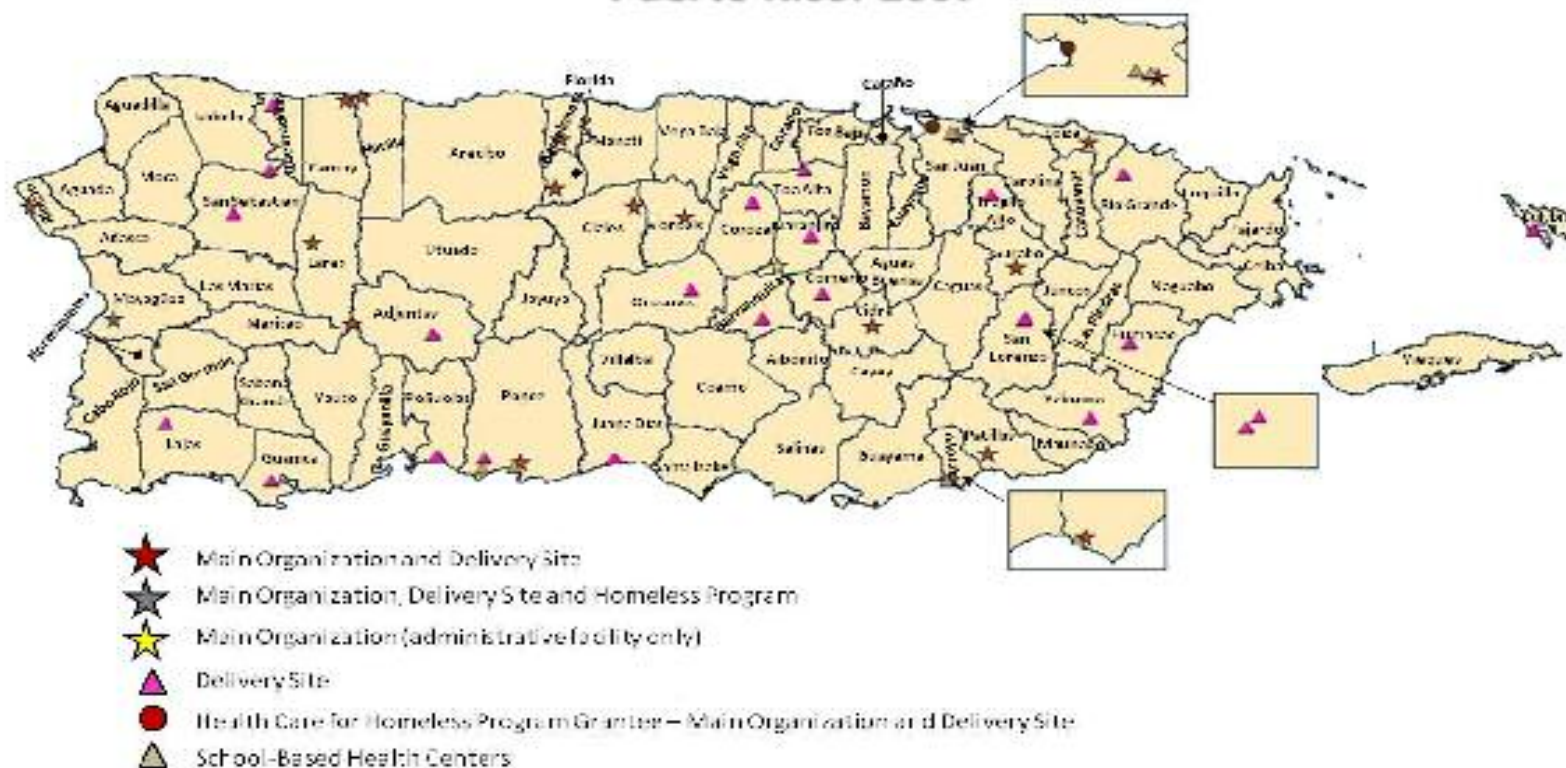
The map displays the geographical distribution of nonprofit organizations across the municipalities of Puerto Rico in 2007. Each municipality is labeled with its name and the corresponding number of organizations. The map uses a color-coded system where orange dots represent the locations of the organizations. The distribution is uneven, with higher concentrations in certain areas like San Juan, Ponce, and the northern coast.

*Numbers represent Nonprofit Organizations
Source: Nonprofit Organizations in 2007: Economic Strength, Puerto Rico
Prepared by: Estudios Técnicos Inc.

Source: Nonprofit Organizations in 2007: Economic Strength, Puerto Rico
Prepared by: Estudios Técnicos Inc.

Figure II-40

Primary Health Care Center Sites Puerto Rico: 2007

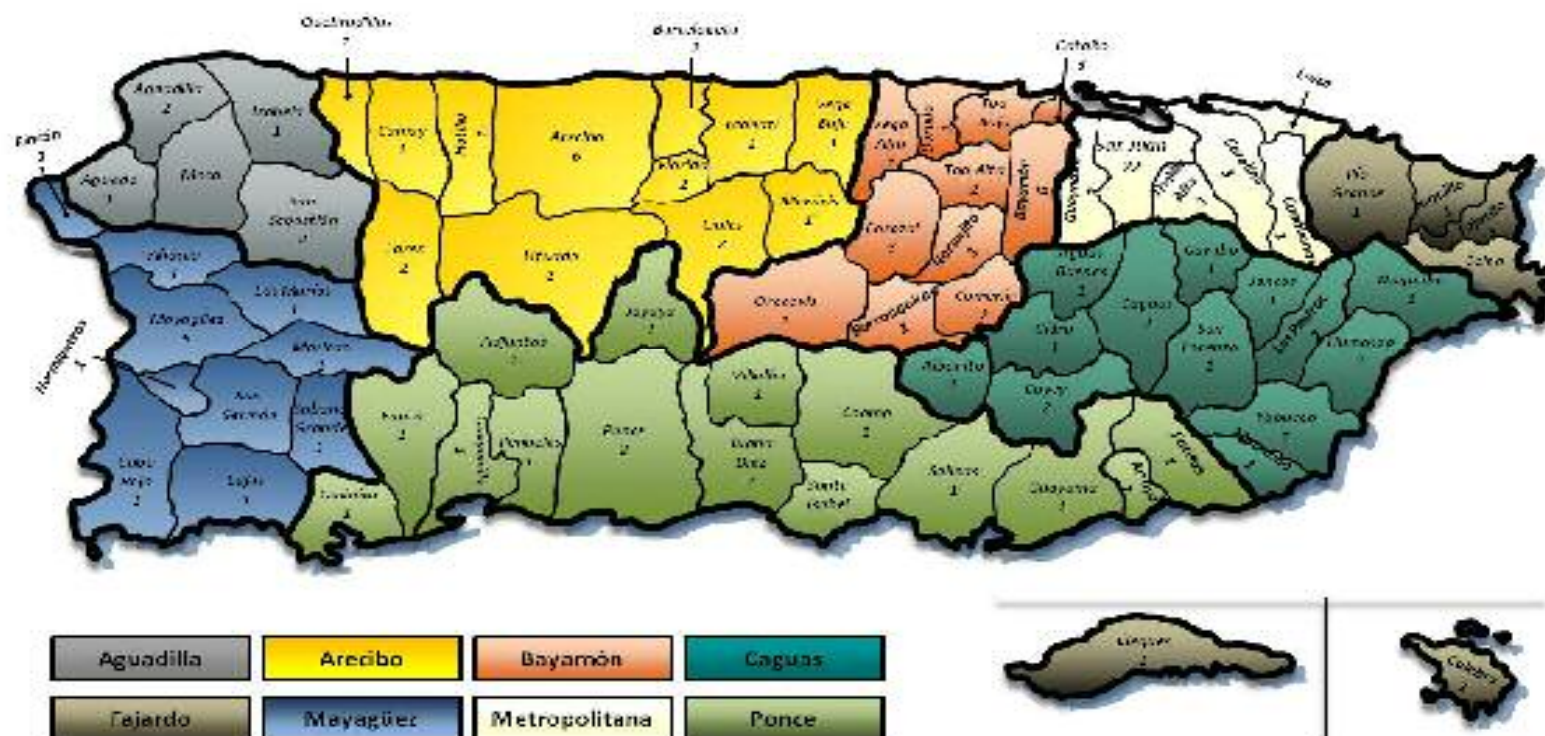


Sources: ASPPR Membership Information, HRSA BPHC Uniform Data System Puerto Rico Rollup Report 2007 and Section 330 of the Public Health Services Act (42 USC 254b).

Prepared: ASPPR, Planning and Development Program, February 2009.

Figure II-41

Primary Health Care Facilities by Health Regions Puerto Rico: 2009*



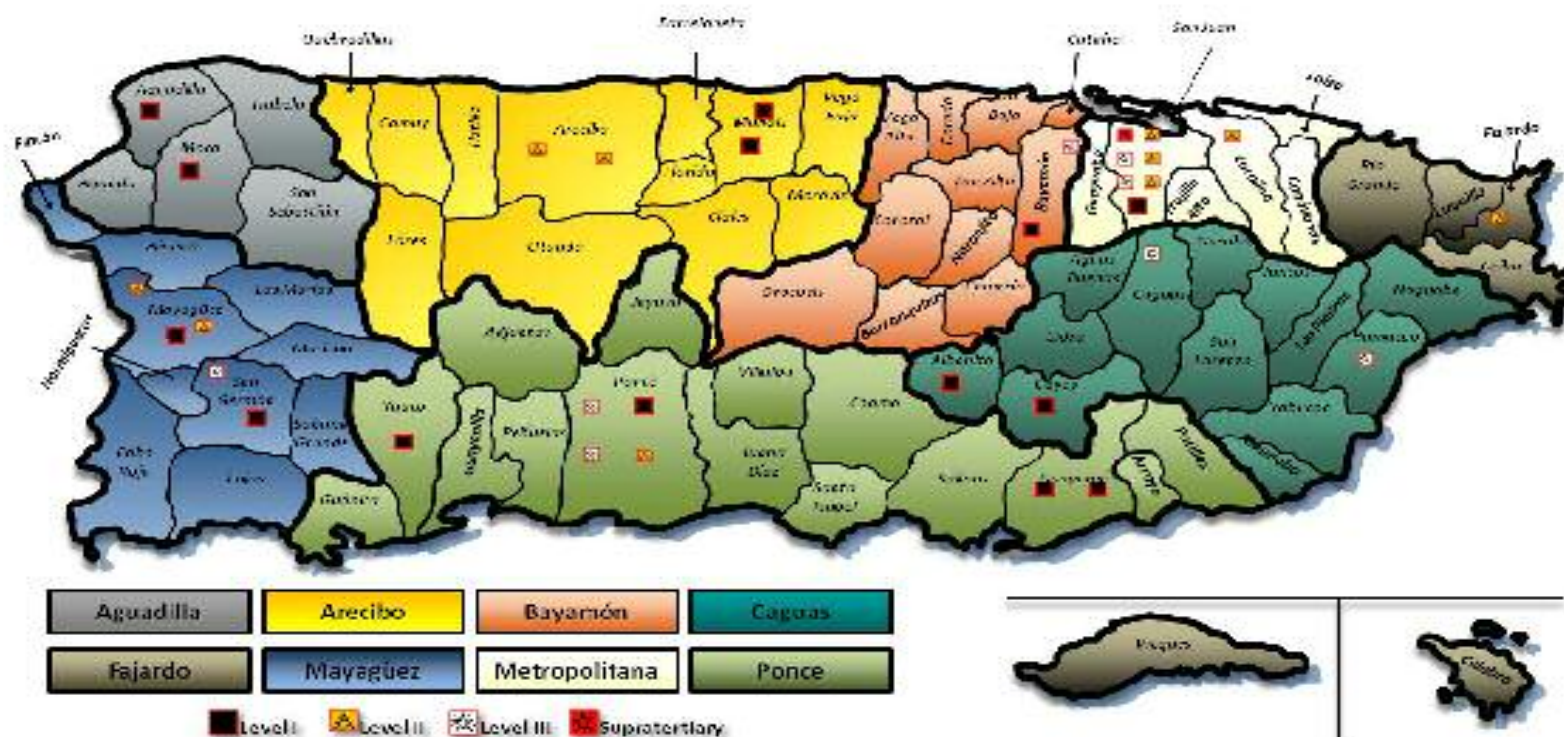
*Data for 2009 is preliminary

Sources: Office of Preparation and Development

Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Figure II-42

Geographical Distribution of Participating Hospitals According to the Level



Sources: Hospital Capacity for Perinatal Care Services in Puerto Rico, 2008
 Prepared by: Monitoring and Evaluation Section; Division of Maternal and Child Health.

Table II-1

Collaborative agencies/programs with PRMCH		
Puerto Rico Health Insurance Administration (ASES, Spanish acronym)	Public Health Emergency Response Preparation and Coordination Office	United Funds of PR
Council for Hereditary Diseases of PR.	Early Head Start	The three health insurance companies that are providing the services for the population with the GIP: MCS, Triple S and Humana
March of Dimes	COPRAN	
La Leche League	Primary Care Association and 330	The Behavioral Risk Factors Survey
Department of Education	The Juvenile Correction Administration	HIV Prevention Program
WIC Program	Title X clinics	Rape Victim Centers
LACTA Project	PROFAMILIA	The Oral Health Prevention Program
Department of Family Affairs	Departments of Agriculture	The Immunization Program
Medicaid	Departments of Labor	PR SCHIP Program
Advisory Board of the Midwife Training Program of the School of Public Health	Departments of Housing	The Office of the Patients' Ombudsman
Preconceptional Health Committee	Departments of Sports and Recreation	The Oral Health Prevention Program
American College of Gynecology	Insurance Commissioner	The Dental School
MCS Medical Health Insurance Company	Commission on Nutrition	Identification of Special Health Care Needs Children Project (PININES, Spanish acronym)
Department of Education	College of Nutritionist	
Asthma Coalition	PR Safe Kids Coalition	The Alliance for Health, Active and Well Nourished Children and Adolescent (AHAWNCA)
Advisory Council of Special Education to the Secretary of Education	Fire Department	
State Epidemiologist Office	UPR School of Medicine	Police Department
PR Fitness Program	University Pediatric Hospital	
Administration of Mental Health and Anti-Addiction Services – (ASSMCA, Spanish acronym)	Autism Interagency Committee	
American Academy of Pediatrics (AAP)	Department of Health and Vocational Rehabilitation	
University of PR, School of Public Health	State Council on Developmental Disabilities	
Institute of Developmental Deficiencies of the School of Public Health of the University of Puerto Rico	PR Asthma Coalition	
Emergency Medical Service System	University of Puerto Rico Institute for Developmental Deficiencies	
Justice Department		

Table II-2.aList of Potential Priorities for Puerto Rico, 2010

Position	Potential Needs	Score	Included	Why
1 (P)	Children <18 years neglected and abused	189	Yes	It is increasing at a rapid rate. Stated in priority #6.
2 (P)	Premature births	186	Yes	First cause of infant mortality. Stated in priority #3.
3 (P)	Tobacco, alcohol and drug use in adolescents	181	Yes	Changes in high risk behaviors, decreases violence, suicide, pregnancy, among others. Stated in priority #7.
4 (P)	WRA with STD's	178	Yes	It is a proxy of preconception care. Stated in Priority #1
5 (P)	No use of anti-conceptive methods in adolescents	177	Yes	Increases pregnancy and STDs in adolescents. Stated in priority #7.
6 (P)	WRA victims of domestic violence	176	Yes	Emerging issue. Stated in priority #1.
7 (P)	Pregnancy in adolescents 10 to 14 years	174	Yes	It is a proxy for high risk behaviors in adolescents. Stated priority #7.
8 (P)	Immunization in children < 5 years	173	Yes	Decreases morbidity in the pediatric population. Stated #4.
9 (P)	Birth defects	173	Yes	It is a proxy of preconception care. Stated in priority #1.
10	Suicide in adolescents 15 to 19 years	173	No	It is being measured by a NPM.
11 (P)	Mental health problems in children 1 to 14 years	172	Yes	It is scarcely addressed. Stated in priority #6.
12 (P)	Adolescents 15 to 19 years with mental health problems	171	Yes	It is scarcely addressed. Stated in priority #6.
13 (P)	Low use or no use of folic acid in WRA	170	Yes	It is an indicator for preconception care. Stated in priority #1.
14	Infants deaths	170	No	It is being measured by a OM.
15 (P)	Sexual activity in adolescents 15 to 19 years	170	Yes	It decreases pregnancy and STDs in adolescents. Stated in priority #7.
16	Pregnancy in adolescents 15 to 19 years	170	No	It is being measured by a NPM.

Table II-2.bList of Potential Priorities for Puerto Rico, 2010

Position	Potential Needs	Score	Included	Why
17	Children 1 to 14 years overweight/obese	169	No	It is being measured by a NPM.
18 (P)	Asthma in children 1 to 4 years	168	Yes	Asthma is the most frequent health condition. Stated in priority #4.
19 (P)	Sexual activity in children < 15 years	168	Yes	Stated in priority #7.
20	Unplanned pregnancies	167	No	Considered low priority.
21	Limited services of OB/GYN	167	No	Considered low priority.
22	Neonatal deaths	166	No	Considered low priority.
23	PNC during first trimester of pregnancy	165	No	Considered low priority.
24	Perinatal deaths	163	No	Considered low priority.
25 (P)	Unintentional injuries in children 1 to 14 children	160	Yes	Leading cause of death. Stated in priority #5.
26	Postpartum depression	156	No	Considered low priority.
27	Vaginal infections during pregnancy	156	No	Considered low priority.
28	Uninsured children (<19 years)	155	No	Considered low priority.
29	Suicide in children 1 to 14 years	155	No	Considered low priority.
30	Respiratory infections in children 1 to 4 years	153	No	Considered low priority.
31	Children 1 to 14 years with limited access to pediatricians	153	No	Considered low priority.
32	Use of alcohol in WRA	149	No	Considered low priority.
33	Infants with respiratory conditions	149	No	Considered low priority.
34	Dental cavities in children	148	No	Considered low priority.
35	Limited access to PNC (transportation)	147	No	Considered low priority.
36	Interpersonal violence in adolescents	145	No	Considered low priority.
37	Pregnant women that did not received orientation/education about PNC	144	No	Considered low priority.
38	Breastfeeding	140	No	Considered low priority.
39	Respiratory infections in children 5 to 14 years	139	No	Considered low priority.
40	Gastroenteritis in children 1 to 4 years	137	No	Considered low priority.
41	Absence of dental sealants in children	137	No	Considered low priority.
42	Otitis media in children 1 to 4 years	132	No	Considered low priority.

Note: (P) implies that this is priority for the PR MCH Program.

Table II-3.a

Puerto Rico Department of Health
Auxiliary Secretariat of Family Health, Integrated Services and Health Promotion
Maternal and Child Health Program

Integrated Index of Maternal and Infant Health Status Puerto Rico 2006

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Age	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Gender	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Marital Status	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Income	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Education	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Occupation	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Health Status	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Religion	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Political Affiliation	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Employment Status	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Home Ownership	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Vehicle Ownership	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Travel Frequency	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Waste Recycling	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Energy Consumption	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Food Waste	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62	63	64	65	66	67	68	69	70	71	72	73	74	75	76	77	78	79	80	81	82	83	84	85	86	87	88	89	90	91	92	93	94	95	96	97	98	99	100
Water Conservation	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60	61	62</																																						

Source: Vital Statistics, 2006

Prepared by: SMEISI, Puerto Rico MCH Program

Table II-3.b

Puerto Rico Department of Health
Auxiliary Secretariat of Family Health, Integrated Services and Health Promotion
Maternal and Child Health Program

**Integrated Index of Maternal and Infant Health Status
Puerto Rico 2006**

[illegible]

Source: Vital Statistics, 2006

Prepared by: SMEISI, Puerto Rico MCH Program

Table II-4

Number and Percent of Children of the Total Population by Age Groups

Ages	1980	1990	2000⁽²⁾	2004⁽³⁾	2005⁽⁵⁾	2006⁽⁶⁾	2007⁽⁷⁾	2008⁽⁸⁾	2009⁽⁹⁾	Percent of Total Population (2009)
1 - 4⁽¹⁾	267,592	250,436	295,406	215,873	210,133	204,424	198,249	198,248	194,750	4.9
5 - 9	330,331	316,991	305,162	294,373	289,841	284,942	271,211	267,831	260,751	6.6
10 - 14	338,291	340,128	305,800	304,874	304,169	302,626	304,894	296,516	292,896	7.4
15 - 19	337,134	327,251	313,436	299,286	297,283	296,387	299,488	298,165	295,930	7.4
Total 1 – 19	1,273,348	1,234,806	1,219,804	1,114,406	1,103,431	1,088,379	1,073,802	1,060,761	1,044,327	26.2
Total Population	3,203,956	3,527,76	3,808,610	3,894,855	3,912,054	3,927,776	3,942,375	3,954,037	3,972,438	100.0

(1) Exclude infants

(2) Data Source: US Census 2000

(3) Data Source: Population Estimate of Puerto Rico Planning Board.

(4) Data Source: Source: U.S. Census 2005, Population Division, U.S. Census Bureau

(5) Data Source: Source: U.S. Census 2006, Population Division, U.S. Census Bureau

(6) Data Source: Source: U.S. Census 2007, Population Division, U.S. Census Bureau

(7) Population Estimates 2008, US Census Bureau.

(8) US Census Bureau International Database 2009.

Table II-5

Puerto Rico State Poverty Level Chart, 2010

ASES Poverty Level*		0	1	2	3**	4***
Medicaid Program Poverty Level****		0% to 50%	51% to 100%	101% to 130%	131% to 200%	No Eligible
Family Composition	Net Income *****					
1	400	0 to \$200	201 to \$400	401 to \$520	521 to \$800	INCOMES IN EXCESS OF THE MAXIMUM OF THE LEVEL THREE (3), THERE IS NOT ELIGIBLE TO THE GOVERNMENT INSURANCE PLAN.
2	495	0 to \$248	249 to \$495	496 to \$644	645 to \$990	
3	590	0 to \$295	296 to \$590	591 to \$767	768 to \$1,180	
4	685	0 to \$343	344 to \$685	686 to \$891	892 to \$1,370	
5	780	0 to \$390	391 to \$780	781 to \$1,014	1,015 to \$1,560	
6	875	0 to \$438	439 to \$875	876 to \$1,138	1,139 to \$1,750	
7	970	0 to \$485	486 to \$970	971 to \$1,261	1,262 to \$1,940	
8	1065	0 to \$533	534 to \$1,065	1,066 to \$1,385	1,386 to \$2,130	
9	1160	0 to \$580	581 to \$1,160	1,161 to \$1,508	1,509 to \$2,320	
10	1255	0 to \$628	629 to \$1,255	1,256 to \$1,632	1,633 to \$2,510	
11	1350	0 to \$675	676 to \$1,350	1,351 to \$1,755	1,756 to \$2,700	
12	1445	0 to \$723	724 to \$1,145	1,446 to \$1,879	1,880 to \$2,890	
13	1540	0 to \$770	771 to \$1,540	1,541 to \$2,002	2,003 to \$3,080	
14	1635	0 to \$818	819 to \$1,635	1,636 to \$2,126	2,127 to \$3,270	
15	1730	0 to \$865	866 to \$1,730	1,731 to \$2,249	2,250 to \$3,460	

Table II-6

Diagnoses for CSHCN Program Services

Children with the following diagnoses are eligible for CSHCN Program services:

Neural Tube Defects

Cerebral Palsy

Neuro-degenerative Disorders

Genetic and metabolic disorders associated to neurological manifestations

Muscular dystrophy

Moderate to severe musculo-skeletal anomalies/deformities

Skin and subcutaneous disorders resulting in moderate to severe functional limitation

Hearing disorders

Vision disorders: Strabismus/ptosis, legal blindness

Infants and Toddlers with developmental disabilities birth to age two, inclusive

Table II-7**Checklist for State Performance Measure #03**

FY 20__

**SEVEN INDICATORS DOCUMENTING DATA COLLECTION, ANALYSIS AND
DISSEMINATION FOR ONGOING NEEDS ASSESSMENT**

__0 __1 __2 __3	1. A functional Birth Defects Surveillance and Prevention System is being operating, and key findings needed for public health planning and for engaging the public in preventive measures are reported to stakeholders and the public.
__0 __1 __2 __3	2. a. Biennially the Maternal and Infant Health Survey (ESMIPR) is completely administered to a random sample of postpartum women in all hospitals with 100 or more births, OR... b. Biennially salient findings from the Maternal and Infant Health Survey (ESMIPR) are reported to stakeholders and the public.
__0 __1 __2 __3	3. A functional Epidemiologic Maternal Mortality Surveillance System (SiVEMMa) is operating, and key findings needed for public health planning and for engaging the public in preventive measures are reported to stakeholders and the public.
__0 __1 __2 __3	4. A functional Fetal and Infant Mortality Review (FIMR) is being operating, and key findings needed for public health planning and for engaging the public in preventive measures are reported to stakeholders and the public.
__0 __1 __2 __3	5. a. Biennially the Maternal and Child Health Research data collection process is completed, OR... b. Biennially salient findings from the Maternal and Child Health Research key findings needed for public health planning and for engaging the public in preventive measures are being reported to stakeholders and the public.
__0 __1 __2 __3	6. Annually salient findings from the Integrated Index of Maternal and Child Health by Municipality (IISMIPR) are reported to stakeholders and the public.
__0 __1 __2 __3	7. The Puerto Rico Child with Special Health Care Needs Survey is being conducted at least every five years.

Key: 0 = Not met or no progress
1 = Partially met or some progress
2 = Mostly met or great deal of progress
3 = Completely met or completely done

Table II-8Checklist for State Performance Measure #07

FY 20__

**EIGHT CHARACTERISTICS DOCUMENTING YOUTH DEVELOPMENT MODEL
IMPLEMENTATION IN ORGANIZATION WORKING WITH YOUNG PEOPLE**

__0 __1 __2 __3	1. Staff provided with training opportunities on youth development concepts and strategies.
__0 __1 __2 __3	2. Organizations encourages partnerships and collaborations with other agencies and organizations in order to provide more opportunities an supports for young people
__0 __1 __2 __3	3. Programs are culturally sensitive; they recognize cultural strengths and differences, and meet the needs of diverse population.
__0 __1 __2 __3	4. Young people are viewed as resources and are actively engaged in planning, implementing and evaluation programming
__0 __1 __2 __3	5. There is designated staff to support youth participation (to ensure recruiting, preparing and sustaining young people to be actively involved in the organization).
__0 __1 __2 __3	6. The organization's mission reflects youth development principles.
__0 __1 __2 __3	7. Organization shifts from preventing problems to creating positive outcomes (such as competencies, connections and caring relationships, positive values and expectations, meaningful participation).
__0 __1 __2 __3	8. The organization reached maximum youth participatory level (autogestion juvenil).

Key: 0 = Not met or no progress
1 = Partially met or some progress
2 = Mostly met or great deal of progress
3 = Completely met or completely done